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Conference organised by PACSA's Economic Justice Desk and PACSA's Gender Desk.

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Foreword

This conference on the links between gender, poverty and HIV/AIDS was hosted by PACSA as a result of a research process we underwent with 30 women living in the Mpumuza semi-rural area outside Pietermaritzburg. What struck us during the course of interacting with these women was the power of their stories and the witness of their strength and courage, and their weaknesses too. We began to realise that their voices, and voices like theirs, needed to be heard if policymakers and others involved in HIV/AIDS work were to be able to make decisions that impact significantly on the epidemic.

The research was a joint project between PACSA's Gender Desk and the Poverty and Economic Justice Desk, as the intersection between Gender, Poverty and HIV/AIDS impacts on both of these programmes of PACSA in an everyday manner. A detailed report of Phase One of the research is available from PACSA.

The Phase One report, released in April 2003, caused quite strong reactions among practitioners and academics alike because of the power of the stories it told. The participatory methodology of the research challenged much of the positivist scientific paradigm, with its emphasis on 'objectivity'. The researchers unashamedly told of their occasional direct intervention in a woman's life in response to hearing her story of extreme poverty, starvation or deprivation. This raised the question of ethics in social science research among the poorest, most marginalised group: semi-rural women living with HIV in South Africa.

As a result of the level of interest shown and the quality of the debates that ensued, it was decided to host a conference on the topic of Gender, Poverty and HIV/AIDS. The conference was advertised broadly through various forums, including the internet.

In keeping with the participatory nature of the research, PACSA decided to attempt a new approach in the conference, and we invited people from all walks of life, cultural, language and educational backgrounds. We made a concerted effort to welcome people living with HIV and/or AIDS as we felt it imperative to create a forum where those living with HIV would be able to talk about their experiences among those from NGO, research and government bodies. We tried to create an atmosphere where people would not simply talk about PWAs in their absence, but where a legitimate dialogue was to take place between those directly infected with HIV, and those either HIV-negative or ignorant of their status. It was agreed early in the conference that we were all affected, and thus there was no 'us' and 'them'. The conference was based on the desire to openly seek God's face during this time of crisis, partly through prayer and meditation, and partly through really listening to one another.

We are sad to have to say that half the women who participated in the research with us passed away during the 14 months that we worked with them. It is to them, and the countless others who have also died needlessly, that we dedicated the conference, and that we dedicate this report. It is our hope that it will make a small contribution towards the development of increasing numbers of responses that impact meaningfully on the human face of the epidemic.

Daniela Gennrich,
PACSA Director
and Gender Desk Coordinator

The Memorial Corner where people lit candles and offered prayers for loved ones lost to HIV/AIDS

Editorial: The Real Meaning of *Ubuntu*

HIV is not neutral. It is biased. It impacts on the most vulnerable. Given that this is the case, it makes sense for us all to look at HIV from a non-neutral position. In other words, we cannot address HIV if we do not look at the conditions that make it possible for HIV to continue to have a devastating effect on communities. It is clear to most now that gender and HIV are linked and that poverty and HIV are linked. Given that women are, in general, the poorest of the poor, it is vital that we look at HIV within this context.

Statistics show that in South Africa, between 1500 and 2000 new infections take place every day; more than 600 people are dying every day from HIV related conditions; about 800 babies are born to infected mothers every month. According to UNAIDS and WHO, 58% of all HIV positive adults in Sub Saharan Africa are female, and new information on the link between gender, poverty and HIV/AIDS reveals that there does indeed appear to be a strong link between these influencing factors on women's vulnerability to HIV infection. It is these realities that led PACSA to conduct its research on women, HIV and poverty and to host the conference: Gender, Poverty and HIV/AIDS.

The Conference

The conference took place over two days in Pietermaritzburg. As the recorder and as an outsider, I can sincerely say it is one of the best conferences I have ever attended. There are reasons why this is so. For me the most important is something hard to capture or hold or see – but you can feel it. This is the spirit – or even better to say in Zulu – uMoya – that was there. There was a unity, a kindredship that overwhelmed me and brought me close to tears many times. I guess it's because God was present at this conference – *kuyacaca ukuthi bekukhona umoya wokuthula.*

Daniela Gennrich, PACSA's director, opened the discussion. Two very special things were offered to delegates: a memorial corner, at which people were invited to light a candle and pray for loved ones lost through AIDS; and a person, a body, to pray with people if they needed it. These things, the simplicity of the conference – it's openness to everyone, its very realness – were the things that set it off to be something special, something guided, something good, and something that will bear even more fruit within the months to come.

A range of organisations attended the conference – community, faith-based, non governmental, governmental – as well as individuals. The topics covered included the municipality's work around HIV; research around women and HIV; practical tools to help ease the burden of HIV, research trials and personal stories. It was aimed at ordinary people and it was for ordinary people - to share, to express themselves, to talk about problems and solutions.

Presenters gave input and participants were given a chance to discuss these.

Phumzile Zondi, an academic and sister living openly with HIV, left us with the following powerful thought – living in fear is like secondary poverty. "If we live in fear, we are poor". She also challenged all of us as activists with the question, "How much have we done to destigmatise HIV?" She emphasised that in order to win the battle, we have to break the spirit of fear.

The Breakfast Briefing

On the morning of the second day, PACSA hosted a breakfast briefing for civil society and Government leaders. The guest speaker, Canon Gideon Byamugisha, a priest from Uganda, shared his life story. He moved people with his account of discovering that he was HIV positive. As a priest, he has spoken about his status in the hope of getting others to be more open. When he introduced him, Reverend Sipho Sokhela (CEO of KwaZulu Natal Christian Council), said that the days he had spent with Canon Gideon that week had been one of the most meaningful times of his life.

Key themes coming out of the conference included:

Blame and Stigma

Cannon Gideon not only contributed to the breakfast briefing but gave input at the broader conference. One of his main messages, shared by others in the room, was the need to move away from blame. He spoke about children who claim that HIV is a disease of their parents, while parents say "if only children would change their behaviour", women blaming men and men saying that women are at fault. He also said he had even heard someone say, "You Africans, stop screwing yourself to death."! And so the cycle of blame and judgmentalism continues.

He also mentioned that perhaps the stigma was a result of a very deep fear, which is a result of the unreal power accorded to HIV and AIDS. He pointed out that we need to reaffirm three things: that HIV is preventable (actually not very easy to catch!), AIDS is postponable (especially with good medical care) and that it is vulnerable (if exposed and talked about openly it easily loses its power over whole communities and can be dealt with.)

Men

A key issue that came up was the need to "de-problematise" men. I understood this to mean that we should stop pointing fingers at men, but instead get them involved in HIV. Someone put it this way, "We must include men and women in a healing circle." The point being made was that while we acknowledge that women bear the brunt of the HIV epidemic, we should not fall into the trap of blaming men. Instead of fighting men, we should get them to change by involving them, getting them to understand the consequences of the epidemic for women. Daniela of PACSA summarised it in the following words, "We must acknowledge the anger and frustration of women and allow the space to air this, but this does not have to mean alienating men."

Government

A strong theme was that of Government and its responsibility. Participants asked the question, "How do we as civil society keep Government accountable for their handling of the HIV epidemic?" The issue of a basic income grant and Government roll-out plans for treatment were discussed at length. Participants spoke about the need to support a basic income grant as the right of every South African to have cash in hand, to avoid the humiliation of total destitution. Participants also spoke about the roll out being limited to those who have access, and concerns were raised about those in outlying and remote rural areas.

The Church

Delegates spoke about the role of the Church. The question linked to this was, "Who is the Church?" Participants spoke about the Church needing to undergo change and that this change required self evaluation. Someone quoted Bishop Purity Malinga who said; "We need to have the courage to do Church differently."

There was talk about 'richer' (financially) Churches collaborating with and supporting those who did not have money. But people also spoke about riches that Churches offer that had nothing to do with money.

Many other issues were shared and discussed. However, what was significant at this conference is that people spoke and people heard. People shared and they learnt. I felt honoured to be there – that God had planned for me to be the one who recorded the conference.

Perhaps it is best to end with the words of that great man (Canon Gideon) who enriched our lives with his presence. He left us with these thought-provoking words: "People think I am a strong man but sometimes I do cry. Because of all the information I have now – if only I had had it then. I passed all the exams and then I failed the HIV test – that makes me very sad. {But} My life is a testimony to the fact that we can fight AIDS."

The rest of this report offers those papers that were submitted in full, as well as abstracts of the other papers. The aim is not to provide any answers to the many questions we all grapple with, as people affected and infected with the virus, but to present reports of research or interventions in relation to issues of poverty, gender and HIV/AIDS and to offer personal reflections and testimonies of positive, life-giving responses.

Gladys Ryan, Editor

Theological Reflection: The Healing of the Bleeding Woman

Phumzile Zondi Mabizela

(Report written by Monika Wittenberg for Impulse*, newsletter of the Lutheran Church in Pietermaritzburg)*

Sister Phumzile was an inspiration. She opened her reflection with the hymn, "Yes, Jesus loves me" saying that she chose this song because she had been living with HIV for a long time. Her reflection, she said, was shaped by her HIV status. One of Phumzile's messages was that of living in secondary poverty – living in fear. She said that if we live in fear, although we may have worldly riches, we are nevertheless poor. She challenged all delegates to consider their role as activists. This is her reflection.

Today I talk to you as an HIV positive person. I am not ashamed to confess it, because I know that God loves me! Recently I was called to a woman who is HIV positive, on the very same morning when I had been to my doctor to discuss my latest blood monitoring results. The doctor helped me understand the link between HIV and depression. I made a conscious decision to fight depression. I just could not afford to entertain it.

On the following day I visited the HIV positive woman. She has a beautiful home with a garden she tends herself. As she welcomed me into her home I was struck by a heavy, negative aura that filled her beautiful home. It was clear that she was not poor, yet I felt she was very poor because of the heavy aura of anger, depression and fear. I found myself personally affected by all the negativity emanating from what should have been a happy, healthy environment.

I was reminded of the woman in Mark 5: 24 - 34, who had suffered from haemorrhages for twelve years. She had spent all she had on doctors who could not help her (v26). In the Jewish tradition her condition made her unclean. After hearing about Jesus, she said to herself that if she could only touch the hem of his garment, she would be healed. Her action violated the social code for proper female behaviour and religious law. This, to me, looks like a very bold step: it does not look like something that could be done by someone who lived in fear. Her condition must have isolated her from others, who feared becoming infected or unclean. But she went ahead and touched Jesus' garment.

After her healing Jesus wanted to know who had touched him. Judging by their response his disciples thought his question did not make sense. But obviously Jesus knew something they did not. Only when the crowd knew her secret – that she had touched Jesus – was she filled with fear and trembling. But the most important issue was that ***she was healed***. Exactly what made her fearful and trembling? Was it the crowd or her confession? Jesus called her "daughter" to show his unconditional acceptance. He acknowledged that it was her faith that healed her.

Coming back to the woman I visited: how can a professional woman with all the resources and skills live in fear of being found out that she is HIV-positive, of being rejected, despised, discriminated against…? She has suffered greatly because of this fear and even attempted suicide. I shared my story with her because I did not know what else to say. I also, of course, represent the very community that had forced her to live in fear. Living in fear is secondary poverty. I was relieved when she decided to share her story with me. It was then that we could discuss the available resources and possibilities for living positively for a long time.

How much have we done in our Churches and communities to destigmatise HIV and AIDS and to eliminate discrimination? Have we created an environment of love and acceptance? Without addressing the issue of fear in the lives of those living with HIV and AIDS we still have a long way to go. This prevents people from asking for relevant help or support; it decreases the chances of people accessing available resources; it promotes a culture of dishonesty between partners. Let us break the spirit of fear by encouraging people to be themselves, giving them the freedom to choose whether they disclose their status or not.

Phumzile Zondi Mabizela is coordinator of the Gender Programme of the Institute for the Study of the Bible.

PACSA Research Project: Gender, Poverty and HIV/AIDS

Daniela Gennrich, Mary Moleko and Lindiwe Xaba

Background to the Research[1]

Many projects working with women, including PACSA's, attest to the increased vulnerability of women in abusive relationships to HIV/AIDS[2]. During 2000 - 2002, there has been an increase in awareness of the powerful impact of factors such as poverty and gender on vulnerability to HIV. This was expressed at the highest level when, for instance, the KwaZulu Natal Provincial AIDS Action Unit focused specifically on men as their theme for World AIDS Day in 2000-2001 ("Men: Caring Enough to Act").

South Africa has the highest level of crimes against women in the world. According to estimates based on police reports in 1999, a woman is raped every 17 seconds in South Africa, and 50% of all women - regardless of race or class - can expect to suffer some form of abuse at some point in their lives. Moreover, on average over 20% of all South African women are likely to have been abused by their partner at some stage in their life, while in Gauteng, a woman is killed by her partner every 6 days.[3] These high levels of abuse against women suggest a reason why the HIV incidence in women is so high. But the problem is not simply the vulnerability of women to HIV infection. Their low social status and vulnerability to abuse make it more difficult to cope with living with the virus.

PACSA's Gender Desk and Poverty and Economic Justice Programme undertook a small qualitative research study. The results of this have been borne out by a recent research study in four Soweto antenatal clinics which revealed that women who were abused by their husbands or partners were 48% more likely to contract HIV than those women living in non-violent households.[4]

Outline of the Research

Lindiwe Xaba presenting the paper on PACSA's Research Project

The research project took place between October 2002 and January 2004. The aim was to answer the questions, "How do women survive" and "What support do they need?" in relation to HIV and poverty. The objectives of the research were:

- to share the real life experiences of the women with decision-makers and others with the power to help improve their situation and that of other women like them; and
- to assess a minor intervention that aimed to strengthen their ability to cope.

The research took place in an impoverished semi-rural area, Mpumuza, between Sweetwaters and Edendale on the outskirts of Pietermaritzburg, and followed the lives of 30 women living there. They were mostly unemployed and lived under very poor conditions. The research was advertised through the

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1. Thanks to Jenny Kuhlmann and Linda Knox, who both spent a great deal of time capturing the data for this research.
2. Cookie Edwards, coordinator of South Africa's National Network on Violence Against Women, quoted in IRIN Africa PlusNews reports, 5/6/2004 (A Gender AIDS posting,
3. Haddad, Bev, 2002 "Gender Violence and HIV/AIDS: A Deadly Silence in the Church", Journal of Theology for Southern Africa, No. 114, Nov 2002, on the basis of research undertaken by Vetten and Bhana. Cited in Gennrich, D. 2004. "The Church in an HIV+ World: A Practical Handbook." Cluster Publications, Pietermaritzburg.
4. 'Gender-based violence, relationship power, and risk of HIV infection in women attending antenatal clinics in South Africa', conducted jointly by US and South African academics and cited in IRIN Africa PlusNews reports, 5/6/2004. (A Gender AIDS posting.)

local clinics, NGOs and HIV support groups, and HIV positive women were invited to volunteer as participants. In the end more than 30 highly motivated women applied and 30 were given the opportunity to become not just research subjects, but participants. The results of the different phases were reported back to these women at specific points, during report-back workshops, which provided opportunities for self-reflection. A more detailed account of the methodology and first phase of the research is provided in PACSA's report on Phase One of the research.[5]

The project took place over about 18 months, in three phases:

Phase One: Two interviews with the 30 HIV positive women living in Mpumuza, which obtained information about their general living conditions as well as their HIV history. (The results of this research are available in the Phase One report.[6])

Phase Two: A third, follow up, interview was made to assess how the women had been coping over the period of 8 months since the first interview, and what impact PACSA's reportback workshop might have had. Ten of the women were asked more in-depth questions in which they told personal stories of how they were coping, and talked about their feelings and attitudes towards themselves, their partners and their lives as a whole.

Phase Three: Two contrastive groups were interviewed, using the same schedule as interviews one and two:

- ten economically more stable women who were HIV positive, living in Pietermaritzburg, with an income of about R5000 per month and with good housing and other living facilities; and
- ten HIV positive men living in Mpumuza or a similar area, mostly unemployed, with poor housing and few facilities.

The women in the main sample were 'poor' in relation to all three factors that contribute to poverty:

- gender: they all had little decision making power and limited choices;
- poverty: they were all economically poor;
- HIV/AIDS: all were HIV positive.

Results

There were some interesting differences in the ways the three different groups coped. Although the samples were very small, a comparative description of some key aspects of their lives is very interesting.

Children's Education

Mpumuza Women:

- a minority had completed school; none had any further education, and several were supervising homework in grades that they had not yet achieved themselves;
- there was a commitment, against all odds, to educate children;
- the women were unable to pay school fees and their children suffered from being excluded, forced to repeat grades, having their reports withheld and punishment;
- these problems were a huge burden and extra stress on HIV positive mothers.

Mpumuza Men:

- Most of them had no children, two lived with their children, but none felt responsible for their education.

Economically Stable Pietermaritzburg Women:

- eight of the ten had completed matric; five had gone on to do further studies and three had postgraduate degrees;
- all their children attended school, and supervision was appropriate.

Support: Welfare Grants

Mpumuza Women:

When they did get grants, these made a huge difference to their lives and ten of the 30 would have lived on nothing if they had not had access to grants.

Some of the problems around grants were:

- ignorance – people did not know enough about them, particularly the Disability Grant;
- seven of the women had not applied for a grant at all, although they were very much in need of such financial support;
- 22 of the women had applied but only 13 had received a grant;

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[5] "Gender, Poverty and HIV/AIDS: How do women survive and what support do they need? Report of Phase 1. April 2003." It is available from PACSA - danielag@pacsa.org.za. A summarised article can be found in Youth For Christ's *Partnership* magazine, June 2003.

[6] As above in footnote 5.

- the women experienced delays, rude welfare officials and corruption at some welfare department offices. In addition, they experienced public humiliation when applying for disability grants, and welfare officials processing applications that came with a financial bribe before attending to others, regardless of how long they had been waiting in queues.

Mpumuza Men:

This was the same as for the women, but all knew about the grants, although only one had tried to apply for a disability grant.

Pietermaritzburg Women:

None of them needed grants at the time of the research, but there were fears about what would happen when they were unable to continue working.

Support: Families, Partners, Churches and other HIV Support Groups

It is significant that, while all the more economically stable women were able to disclose their status and get strong support, the poorer women often almost stigmatised themselves and did not disclose their status for fear of losing whatever financial and emotional support they had from partners.

There was only one person who did not disclose her status to anyone at all, and this was one of the Mpumuza women who was in the most insecure financial position and totally dependent for her survival on those around her.

Family and Friends

Mpumuza Women

12 of the 30 Mpumuza women had had serious conflict with their families as a result of their HIV status, and only eight took the risk of telling their partners. Of these eight, all but two partners left when they heard the news. Only one of the 30 had disclosed her status to her family as a whole.

Mpumuza Men

80% of the men had disclosed their status and less than half of them had had any conflict with family about this and the women in most of their lives were accepting of them.

Pietermaritzburg Women

The more economically stable women took more risks in disclosing their status, and thus also felt more supported by their families.

Relationships with Partners

With regard to relationships with partners, the research found the following:

- men blamed women and women blamed men for HIV;
- poorer people had less stability in their relationships;
- over 90% of all the women had only one partner at a time;
- over 70% of men had more than one partner at a time (two claimed to have more than five at any one time!);
- the women in abusive relationships were less able to negotiate safer sex or have control over their own bodies;
- poorer women were more vulnerable to abuse and less able to assert their rights;
- most lower income men left the relationship once they learnt about their partners' or their own HIV status;
- most women (any income level) stayed with their male partners once the males had disclosed.

Churches, HIV Support Groups and Other Organisations

Most of the women belonged to Churches and most of the men did not. The same applied for HIV support groups. This supports the experience of organisations working with the infected - that very few men come forward for help, preferring to suffer alone and even isolate themselves from their own families.

A disturbing finding was that only three of the 30 Mpumuza women were able to disclose their status in Church. This issue is discussed in more detail in the paper on this subject on Day Two.

Without exception, those involved in HIV support groups said it was an enormous relief to be in the company of others also struggling with HIV, and that it was a help to them as the other members supported them in lots of different ways.

Those who were less economically dependent were more able to take the risk of explaining their status, and those with a better education were more able to explain their stories and thus get better support.

Prevention and Condoms

While all the groups knew about the condom and other preventive measures, only the economically more stable PMB women were able to use condoms consistently.

Mpumuza Women

Most were unable to use any prevention, especially the 12 who were in violent relationships. Reasons for this were related to poverty and dependence on partners, as well as fear of violent abuse.

Mpumuza Men

Only six of the ten men used condoms, giving arguments such as fear that they would be less manly if they used them, or that condoms reduced pleasure.

PMB Women

80% of these women used condoms. One of the two that did not left her partner when he refused to wear them.

Health Care

Although not all those who attended the Communicable Diseases Clinics (CDCs) at hospitals or clinics felt that their health had improved dramatically, all but one were more than satisfied with their treatment and the conditions.

Mpumuza Women's Comments to the Communicable Diseases Clinics

- "Counselling and support was excellent! THANK YOU"
- Disability Grant: "Please start at Stage 3 – delays and problems mean we often don't get grants until very late."
- "I have never managed to see a doctor, even when acutely ill. What are the criteria for seeing a doctor?"
- "Dr. Kocheleff respects me and really listens. He also goes to great lengths to use translation where necessary. He really takes his time, and I am grateful."
- "Please make sure you always have the medicines in stock – some of us cannot come back again without transport money."

Unfortunately, of the 30 Mpumuza women, 15 had already passed away during the 18 months of the research. Moreover, one of the economically more stable women died during the weeks between the Phase Three interviews and the conference report. This points to the urgency of the need for antiretroviral treatment. It shows that supportive treatment and even the excellent protocols involving primary and secondary prevention of the most common opportunistic infections, offered by the CDCs, is not enough. All the women in this study were highly motivated and worked hard to change their lifestyle - yet still half lost their lives within the short space of 18 months. Several of these left orphans behind.

In Summary

In answer to the questions we sought to answer in relation to impoverished women living with HIV; "How do women survive" and "What support do women need?", the following are some observations, in summary:

What Helps?

SUPPORT is the most important thing of all. This comes from:

- God, even for those who feel that no people can be trusted;
- families;
- HIV support groups (especially women);
- professionals;
- the Church ("as long as they don't know my status"!)[7]

All the participants got some support from family, colleagues and Church (and some at work), but there was less for those from poorer communities. It is not clear why, except that it may be related to the fear of asking for support in case of rejection and financial disempowerment, or perhaps to the lower educational level of the communities in which the poorer participants lived.

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[7] A full report on the church and the women from Mpumuza living with HIV/AIDS is provided on page 29.

What Hinders?

- poverty;
- social disempowerment: gender (and poverty);
- problems gaining access to Government and other resource agencies;
- personal disempowerment (internalised oppression).

Some of the above obstacles are explained further below:

HIV/AIDS and Poverty

- Poverty limits access to resources, health care, nutrition and education.
- Economic dependence often results in vulnerability to sexual violence and lack of HIV prevention (fear of abandonment and further abuse).
- Economic dependence is also a factor in disclosure – because of the fear of being abandoned by partner, family, community and Church, a person may stigmatise themselves.
- Many experienced increased depression, anxiety, loneliness and poor self-esteem. Some even expressed feelings of self-hatred and anger in addition to the expected feelings of resentment against loved ones who refused to accept them.

Lack of Social Power (marginalisation)

- Most of the poorer participants felt unable to change their situation (economic and social dependence, at the mercy of disgruntled bureaucrats).
- There was a lack of trust and communication between partners.
- Men, generally, had patriarchal attitudes and often simple disrespect which frequently resulted in conflict and loneliness.
- Poverty exacerbates the impact of HIV/AIDS, but it is also further impacted by HIV/AIDS.

> *"It is dangerous to look hungry. It makes people want to kick you"* (Oscar Wilde, *Down and Out in Paris*)

Government and Other Resources Available in the Mpumuza and Surrounding Areas

- Very little is available to people in outlying areas in a form that is easily accessible.
- There is a lot of ignorance about what is available in poorer, less educated, more outlying areas.
- People find it difficult to access grants and poverty relief schemes. This is sometimes due to unhelpfulness and delays in Government bureaucracy. People are also confronted with disrespect and find this disempowering, contributing to depression and frustration.
- There is some confusion about Government policy about HIV staging and when people are entitled to Disability Grants. As a result, doctors appear not to make consistent decisions, and this confuses people. Incidents are also reported of an AIDS sick person dying before their grant comes through because many people believe they have to be completely disabled in order to qualify. Another important argument presented by the participants is that, if they had earlier access to the disability grant, they would be more likely to delay the onset of last stage AIDS and continue to care for their children for longer.
- There was a strong plea for the Disability Grant policy to be reviewed to be more life-giving to patients with a degenerative disease, as it was clearly designed for chronic conditions that did not necessarily result in death.
- Ignorance about rights to education (poverty, orphans, etc.) is another factor and people have experienced a lack of sympathy (and even cruelty) among school principals.

Sense of Personal Disempowerment and Isolation

- This is linked to poverty and lack of education. People in both the Mpumuza samples felt unable to access resources or find support beyond the minimum.
- More educated women, on the other hand, were able to even establish their own support groups and make arrangements for adoption of children, amongst other things.

Conclusion

We were very humbled by the immense courage and dignity of the women we have been working with, and this has led us to reflect deeply about methodology in HIV/AIDS research and implementation of projects.

We challenge all people involved in HIV/AIDS work to conduct self-evaluations of policies and practices. We need to ask ourselves honestly: "To what extent is our work based on the realities of the bulk of people living with HIV/AIDS in SA?" and

"What motivates us?" We believe it is vital that people living with HIV/AIDS are involved at all stages of planning and implementation, and that decision makers take seriously the call to LISTEN. Our constant choice related to the services we offer and the way we work with people is:

Do we bring healing
(deeper than bodily),
or speed up death
by increasing stress?

End Note: A Reflection on HIV/AIDS Research Methodology: Questions of objectivity and ethics in the context of suffering

Traditional attempts to maintain 'objectivity' and thus a distance from research subjects, while laudable as theoretical concepts, have been questioned by the immensity of the suffering of those with HIV or AIDS whose energy and time researchers demand. This raises an ethical question about the use of research – to inform the world of academics and advance theoretical knowledge, or to improve the lived realities of people like those in one's sample?

While most social science research claims that the aim is to improve the lives of people, this is often achieved at the expense of those who have the misfortune of becoming the research subjects themselves. More often than not, the lives of those research subjects are not significantly or measurably improved by the questioning or observance of academic researchers, and this can lead to a sense of humiliation and even further disempowerment.

We have tried in this research to take into account the immediate needs of the research subjects to become active participants rather than passive objects of the research. In this way we have built in a process of helping the women themselves to use the results of the research to make decisions to improve their own lives.

We also found on a few occasions that the women were in deep financial and personal crisis, and not to have responded (by later bringing clothes to feed naked children in one case, or a basic food parcel and helping to get access to Hospice services) would not only have been unethical, but immoral, in this context.

One immediate result of the report back workshops has been that the Mpumuza women have realised the benefits of meeting and talking together, and those who are still alive have formed their own HIV support group. It is representatives from this support group that addressed the conference, and their input is included below. The presentation itself talks about the benefits of the research for them.

The Thuthuka Support Group

By Zandile Malembe and Zinhle Nxiba

The Thuthuka Support Group was formed after the PACSA research project was completed in January 2004 by the remaining research participants from Mpumuza. They meet regularly in the Church pastored by one of the researchers.

The preceding research report is incomplete without the perspective offered by the research participants themselves. The two speeches below were given at the conference by two members of Thuthuka, after a series of meetings at which the group decided on the most important points they felt needed to be heard.

Zandile Malembe

To the dignitaries who have made it here today from the various Government departments and non-governmental organisation, ladies and gentlemen I greet you all in the name of our Lord Jesus Christ. I thank PACSA for giving us this opportunity to be here on this prestigious occasion and for giving us a breather.

I am Zandile Malembe, one of the 30 people who were interviewed by the various members from PACSA. Our age groups are between 25 and 40. I am here on behalf of the Thuthuka Support group which was started in January 2003 after some deliberation. We meet once a month at the St Martin's Anglican Church in Edendale.

I have been living with HIV for four years now. In our support group, not even one of us is employed. Many of us are renting one roomed flats because our family members and relatives don't want anything to do with us. Though a few of us are still living with our family members or relatives, they are still coming to terms with the situation put before them.

Many of us are alone - partners left us when they heard of our status. With that said, we thank the partners who have stood by us in this, our time of need. This shows that there may be a lot of males around, but men are hard to find. Gentlemen, we urge you not to desert us when the going gets tough. It will all come right in the end.

Head my plea and please treat us women the way we need to be treated: with respect!

Our Needs

Department of Welfare:

We request assistance in accessing "Grants"

- The application process takes too long, many receive the grant when they are too sick to use it, and some even when they have passed away.
- We request that we be given the disability grant before we reach the fourth stage. By then it is usually too late - we are weak, hungry, and too sick to do anything on our own.

Moeti Lesuthu chaired Session One

Department of Education

- We ask of the Education Department not to expel our children from schools when they can't afford to wear school uniform.
- Teachers / Principals, please give our children their school report cards even when we haven't paid the school fees.
- We plead with the ministers and directorates of the different Government departments to hear our cry and empathize with our situation and us. Many of us don't receive the disability grant. We survive on the R160 a month from the childcare grant.

This is where I stop.

Zinhle Nxiba

I have been living with the virus for two years. I am also a representative of the Thuthuka Support Group. I would like to thank the nurses and counsellors from the Department of Health who have helped us, especially in the Edendale Communicable Diseases Clinic, Embalenhle and Caluza Clinic, as well as the Msunduzi Hospice Association – Edendale branch

Even the doctors at Greys hospital were very helpful although there weren't enough. We request that they keep vitamin tablets for us because we live on them. We go to the hospitals many times and each time we go we are told to come back the next day. We do not have transport money and most of us walk to these places.

We are hearing rumours about Antiretroviral drugs. We are told that they are very powerful and can maintain ones health for a long time. We hope all these are not just rumours and that it will happen

Our Needs

Religious Organisations

- ✞ We request freedom to come to Church.
- ✞ We request that time be set aside in Churches to talk about HIV and AIDS. We need to feel free amongst Christians.
- ✞ We need people who will teach our congregation about the virus so that our people will have knowledge.

From our families and the community

- ➢ We need you not to judge us, but to welcome us as we are because we love you.

Zinhle Nxiba

- ➢ If we don't talk to anyone we get sick.
- ➢ We did not get the virus by behaving badly
- ➢ We thank you for the opportunity we have been given by PACSA to air our views.

FORWARD WITH PACSA FORWARD

African Women's Lack of Power to Negotiate Safe Sex

By Gatumo Ngogo

When asked about the source of the AIDS pandemic, Vesi responded that ***ngculazi*** *was said in his area to come from the cities and to be caused by sexual relations between men and women. It was believed that the morals of the women were loose in the cities and that* ***ukuhlela*** *(contraceptives) had given them the opportunity to sleep around with no fear of pregnancy. "What the women fail to realize" he said, "is that such diseases cannot be controlled by pills" (from Bulletin for Contextual Theology in Africa, vol. 7 no. 1, March 2000). It is clear from this quote that while it takes both a man and a woman to have intercourse (unless it is the case of homosexual intercourse) women are blamed for HIV.*

This presentation focuses on African women's lack of power to negotiate safe sex. Safe sex here means sexual encounters that are less likely to lead to HIV infection. African women refers to Black women.

There is a link between gender bias against women and poverty amongst women. There is also a link between poverty, gender bias against women and HIV infection. Statistics show that more African women are infected with HIV than men (58% in Sub Saharan Africa according to UNAIDS, 2003). Infection among women may come as a result of blood transfusion, contact with body fluids such as blood, and secretions during sexual encounters. In Africa, most infections are due to sexual encounters between men and women. This implies that if no African women ever had a sexual encounter, there would be very few African women that are HIV positive today. Do African women have power to negotiate safe sex? If they do, why are they the majority infected by HIV? For me, the reason is that most African women do not have the power to negotiate safe sex because of various factors which I discuss below.

Ignorance

Dudu:

"My husband used to work far away and came home only once a month. A year ago he came home and did not go back because he was sick. I looked after him until his death. When I learned that he had AIDS I cried, knowing that I too was now infected. I have not had sex with any other man."

Cultural Values – Wife Inheritance, Wife Cleansing and Polygamy

Mary:

"After my husband died, the elders arranged for me to marry his brother. They all knew that he had died from AIDS, but they said that it is our custom and we must do it. Since we are Christians, the pastor came home to pray for me to start the relationship with my brother-in-law who was already married."

Unfaithfulness

Lerato:

"My husband used to work with a company that took him to different towns. One day I heard that my husband had an affair with another woman. I hoped that he would be cautious enough to wear a condom. Sometime later I applied for a medical insurance. It was turned down. I became suspicious about my health and went for an HIV test. I tested positive. When I told him, he cried loudly. He said he had thought that he would not infect me."

Unwillingness to Wear a Condom

Jane:

"I used to stay with my boyfriend. He used to have other girlfriends. So I demanded that he should wear a condom when we have sex. But he refused. He said that if I loved him and had no other boyfriend, I should not ask him to wear a condom because he liked 'flesh to flesh'. My boyfriend used to get sick. One day he went to Greys hospital and was told that he was HIV positive. One year later he passed away. Later in 2001 I went for the test and tested positive. I felt angry. I asked, 'Why, God?'"

Rape

Sindi:

"The first time I experienced a sexual encounter was when seven men raped me. I was hospitalized for many days and went through counselling. After that I have been raped three times. I do not know when I contracted HIV, but it must have been when I was raped."

How can Women be Empowered in the Following Relationships?

- A woman who believes that she cannot say no to her husband because he is the one God gave and she has no right to refuse.

- A woman who, even after discovering that her husband is having sex with other women - who perhaps are HIV positive - will not confront him for fear that he might desert her for another woman. She has no job and does not see herself starting life all over again if she divorces him.
- A young girl who is sexually and physically abused by her boyfriend but refuses to leave him because she is economically dependant on him. He provides for all she needs and she fears that if she leaves him, another girl will take over. She knows that he has been seeing this girl secretly.

Conclusion: Power as Central

These stories highlight the issue of power. A person who is ignorant about HIV may not know what safe sex is. Ignorance of one's right can lead to one consenting to have sex even with someone who may be HIV positive. Most men who force women to have sex with them claim that African culture allows them to have sex as they please. Unwillingness to wear a condom is a major hindrance to HIV prevention. One who refuses to wear a condom violates the rights of his or her sexual partner. It is crucial that looking at power relations and the imbalances between men and women forms part of our understanding and work around HIV.

Community Transformation in the Context of HIV and AIDS: Experiences in the Rookdale Pilot Site near Bergville, KZN

Pastor J Nkutha, Mrs Mbatha, C Kerry
uThukela District Child Surivival Project,
World Vision & USAID

The HIV /AIDS epidemic has created a context of despair in many communities. People feel lost and without hope. In the Rookdale pilot site, an innovative approach has been introduced to change this. It is called Transformational Development, and was developed by M Wiltshire. This transformational approach is being used to fight poverty and HIV/AIDS in the pilot site in rural Okhahlamba.

For the past 12 months, the pilot project has worked using context to try to bring about change. By context we mean the state of mind from which behaviour flows. This can be further explained: “What you think determines who you are, and who you are is revealed in what you do”. People always do what they think is right for them. The desired shift in context involves moving from death, dying and stigma - with no hope, no care and no healing - to wellbeing: physical, social, psychological, spiritual and developmental.

Having a vision is important for making this shift. For the people of Rookdale, the vision that inspires is a transformed, future-focused community where a context of wellbeing is created, so that everyone can experience unconditional love, faith in God, hope and the unlocking of people’s potential.

The results have been amazing in the community where this idea was tested. The power of vision has helped give the community of Rookdale a new direction. Transformational behaviours such as unconditional love; non-judgmentalism; clear intention; recognising the unique purpose of each person; acknowledging the limitations of cause and effect thinking; detaching from the outcome; and creating success through peace, love, joy and harmony all helped them walk this journey.

As a result of the training community members have been able to start ten projects: Transformational Leadership Training Project, Coaching Project, Support Group, Garden Project, Schools Project, Home Based Care, Spiritual Project, Small Businesses Project, Orphans Project and One Stop Centre Project. These projects are systematically planned and implemented.

One such project is the Orphans Project.

Orphans Project: "Leaders of Tomorrow"

Outcomes from pilot projects:

- Piloting of this project resulted in three pilot projects for orphaned, vulnerable youth (aged 15-25). The first group has 34 members, the second 18 and the third 23. We are researching with the first group.
- Each group has its own vision, mission, core-values, leader, manager and milestones.
- Each community has a community committee, with representatives from the community, promoting children’s rights.
- Each community committee has its own vision, aiming to help vulnerable children and youth in obtaining their rights.
- The Orphan program has been renamed “Leaders of Tomorrow”. This was welcomed by the children, to fight stigma and eradicate the misconception of vulnerability.
- Each group initiated a chicken project to facilitate saving and a gardening project for food security/ saving.

Training with the children involved and community committees:

- Selected transformational leadership training was provided which enabled each child to develop their own vision for their own life.
- Health messages include nutrition, grants available and HIV/AIDS.
- Children were trained in bookkeeping, as they have to keep records of the group business
- Some children were trained in computer and facilitation skills. Children and committees were also trained on how to manage their own small businesses.
- A community committee assists youth in their projects and encourages participation.

Other activities with the children and youth:

- Research:
  - Home visits to homesteads of children.
  - The senior researcher (an anthropologist) trains children in theatre. As a result, the children have produced a video, *Umdlalo Wethu*, meaning "our game".

What we have Learnt from our Project about Gender, Poverty and HIV/AIDS

- Women hold most responsibility in vulnerable homesteads, looking after the homestead and children. For example, most children are left with their grandmothers.
- When parents or children are sick women take responsibility of looking after them.
- Orphaned children are often forced to care for their siblings. This includes performing all household chores and motherly duties.

How do we link research and intervention?

We listen to children's voices and facilitate what they identify as the way out and then move forward. They receive assistance from the community committee when requested. We offer training if the committee requires it, depending on the availability of skills and funding.

Conclusion

As the old context shifts, new behaviours emerge in the group. It is at this stage that coaching individuals and groups plays a very important role, as it allows the new behaviours to take root. It is context that produces behaviours, and new behaviours will occur naturally and remain as long as the new context prevails.

Transformational training – a personal experience

Mrs Mbatha shared her experience of how transformational training helped her personally. Before she had the training, she was afraid to speak openly about her HIV status, and to disclose her status in public. After the training, she realized that being HIV positive is not a death sentence, and that she could live a normal life.

She was coached to live transformational behaviours and learned to use transformational tools to stop dwelling on the past and concentrate on the future. She was then able to disclose her HIV status openly, and is now supported by her husband and other Support Group members. She has started a Garden project and a small business. Through this she has been able to generate income, and thus alleviate poverty.

Microenterprise Development and Sexual Risk Behaviour: Experiences from Okhahlamba

By Thukela District Child Survival Project, HIV/ MED Grant Amendment Project, World Vision, USAID, DBSP

Presented by Claire Kerry and Zanele Mchunu

Zanele Mchunu

Women in Okhahlamba Municipality in northern (rural) KZN have consistently reported feeling at risk of contracting HIV, despite knowing how the virus is transmitted and how to prevent getting infected. The reasons they gave were socio economic and linked to gender and poverty.

In order to address some of the economic constraints, Microenterprise Development (MED) training was offered to community members to free them from economic dependency on men. In particular, women from households where people were ill, or who had taken in orphans, were trained. About 400 entrepreneurs were trained throughout Okhahlamba Municipality. These trainees entered the programme with R50, and started a business. They received training for about a month (theory and practice), and then had 12 months of follow up or mentorship. Some trainees accessed Microfinance for their businesses.

At the time of evaluation, 74% were still in business, and 57% had rising profits. They also had an increased ability to save. Trainees who had experienced a household crisis in the previous year often were able to 'weather the economic storm' through their businesses.

There was no project intervention to address sexual risk behaviour. However, women were no longer economically dependant on their partners, thus reducing one of the causes of risk behaviour identified by women. An anonymous self-administered survey and focus group discussions were held to discover what effect being able to run a small business had on these women and their households. It was found that many indicators of risk behaviour remained the same, even when women were more economically independent. However, it was found that women who had been in business longer disagreed that their partners had control over sex, and did report using a condom at last sex. Fewer women running businesses reported being sexually active than women in the wider community.

Focus group participants said that women were dependent before the training, and after MED training were independent; had less time for sex; were not disinherited if their husbands died; were more assertive; and had a higher status in the community. If they were not already in a relationship, they could stay independent. If they got 'new' partners, they were more able to negotiate safer sex. However, everyone agreed that it is virtually impossible to introduce condoms into long standing relationships.

MED training can help women find solutions to the economic effects generated by HIV, but risk behaviour is complex. Desirable effects for risk reduction would require partner involvement, communication skills, and having a sense of one's future.

Agricultural Innovation, HIV/AIDS and Food Security[1]

Kees Swaans[2], Michael Malinga[3], Monique Salomon and Jacqueline Broerse

Kees Swaans

You do not have to be a health practitioner to take on the fight against AIDS. NGOs in agriculture can make a difference by helping people improve their livelihood and reduce their vulnerability. This article shows the gendered nature of HIV/AIDS, and outlines how it impacts on agriculture and food security; it looks at strategies NGOs can use to address HIV/AIDS in their work in agriculture; it presents some experiences of the Farmer Support Group, an NGO in sustainable agriculture and natural resource management; and finally closes with an outline of a recently initiated project in Msinga sub-district.

The Face of HIV/AIDS

Fourteen million people (30%) in South Africa experience food insecurity.[4] HIV/AIDS in poor communities makes this worse, as people are weakened by the disease and cannot work or engage in any food production activity. At the same time, poverty and food insecurity lead people to search for jobs as migrant labourers and other non-farm activities, making them more susceptible to HIV/AIDS.

A household affected by HIV/AIDS has increasing constraints on its time and resources. Even if it keeps its land, it may not be able to look after it properly. It struggles for day-to-day survival and caring for others, doesn't have the 'luxury' of engaging with long-term development efforts and is in danger of becoming invisible from development interventions.[5]

Women and girls are most affected by HIV/AIDS. Firstly, they are more susceptible to HIV transmission because of their physiology (the way their bodies are built), social and cultural power imbalances, and economic dependence. Secondly, they tend to bear the extra burden of caring for others, looking after the home and food production. The stigma attached to HIV/AIDS makes things even worse as assistance from the extended family and the community, their main safety net, is cut.[6]

HIV/AIDS in Agriculture

HIV/AIDS has a huge impact on food security in rural households and seems to affect agriculture in a bigger way than it does other sectors.[7] HIV/AIDS is affecting agricultural production[8] due to:

- less people in the household being able to work;
- traditional social security mechanisms being changed, and people having to get rid of assets (e.g. for medical care and funerals);
- the loss of indigenous farming methods, knowledge, and specialized skills, practices and customs;
- death and illness among staff of rural institutions and support services;
- smaller crops and less livestock;
- loss of biodiversity (because of having to reduce crop varieties to cut down labour [9]).

HIV infected individuals have higher nutritional needs than non-infected individuals, particularly with regard to protein (up to 50% increased) and energy

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1. Parts of this article have been published before in MIDNET-newsletter, September 2003.
2. Department of Biology and Society, Vrije Universiteit Amsterdam, the Netherlands
3. Farmer Support Group, Scottsville, South Africa
4. Mullins, D. (2001). Land reform, poverty reduction and HIV/AIDS. Paper presented at the SARPN Conference on Land Reform and Poverty Alleviation in Southern Africa. 4-5 June 2001. Pretoria.
5. Mullins, D.
6. UWESO (2001). Artisan Training and U-sore. UWESO, Kampala.
7. IFAD (2001). Strategy paper on HIV/AiDS for East and Southern Africa. IFAD, Rome.
8. Topouzis, D. and J. de Guerny
9. FAO (2001). Indigenous knowledge – a key weapon in fighting HIV/AIDS. Food and Agriculture Organization of the United Nations. Http://www.fao.org.news/2001/011108-e.htm

(up to 15%). Poor people, especially the rural poor, are even more vulnerable because they are more likely to be malnourished even before they are infected.[10]

Strategies in Agriculture to Reduce Vulnerability

Agricultural and rural development projects can reduce vulnerability to HIV in many ways:[11]

- developing a comprehensive package to prevent HIV transmission;
- assessing the impact of HIV/AIDS on labour productivity, levels of savings, health care expenditure, and family readiness to invest in agricultural production;
- analysing and targeting groups vulnerable to food insecurity;
- gender sensitisation;
- empowering communities to take better care of the vulnerable, including people living with HIV/AIDS, AIDS widows and orphans;
- promoting labour extensive (using more people with less cost) and low-input production technologies;
- training agricultural facilitators and extension workers in
  a) the study of the impact of HIV/AIDS on agriculture, and bio-medical issues related to HIV/AIDS, and
  b) group discussions with farmers on community action on HIV/AIDS;
- using farmer field schools and farmer study groups to address broad community issues, including HIV/AIDS; and
- incorporating AIDS affected households in development projects for vulnerable groups.

A short-term strategy should address the biomedical and behavioural factors, whilst a long-term strategy should address socio-economic and macro issues.[12]

Some of the more promising methods that have been developed in response to HIV/AIDS, taking people through a process of change, are Stepping Stones, Transformational Development, and the Farmer Life School. Stepping Stones is a training package in gender, HIV, communication and relationship skills. It is also a life skills training package, covering many aspects of our lives, including why we behave the way we do, how gender and other issues influence this, and ways in which we can change our behaviour, if we want to.[13] Transformational Development is an approach designed to fundamentally transform the context, by giving individuals and groups of people at all levels the technical, cognitive, and conceptual competencies to do so, and to take control of their own future. Farmer Life Schools originate from Farmer Field School approaches. These are discovery based learning approaches to help (groups of) farmers gain a deep understanding of ecological concepts as well as their practical implications. In Farmer Life Schools, the same processes have been translated to HIV/AIDS and other livelihood issues. In relation to gender, peer education has been promoted in conjunction with sexuality education to create safe spaces for girls and women to work on gender identity and social issues, and gain skills to act assertively in situations in which they are vulnerable.[14] So far, however, there has only been limited experience with these methods in the field of HIV/AIDS and agriculture.

One of the outcomes of a recent workshop on HIV/AIDS and agriculture was that good practice should be based upon what works, not merely on seemingly good ideas.[15] We need more experimentation and creative approaches, backed by evidence of successful interventions. These can then influence policy and practice more widely. Action research was mentioned as one way of assessing interventions to develop understanding of what does and does not work in specific situations. The need for action research has been taken up by RENEWAL (Regional Network on AIDS, Rural Livelihoods and Food Security) in a call for proposals on HIV/AIDS and Food Security in Southern Africa.

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[10] Barnett, T., and A. Whiteside (2002). AIDS in the Twenty-First Century: Disease and Globalisation.. Palgrave Macmillan, Houndmills, Basingstoke, Hampshire/New York, NY.

[11] Topouzis, D. and J. de Guerny

[12] Tallis, Vicci.

[13] See http://www.steppingstonesfeedback.org

[14] Adams, H., and A. Marshall (1998). Off-target messages. Poverty, risk and sexual rights. In: Agenda. AIDS: counting the cost. Vol. 39, 1998. Durban. p.87-92.

[15] HSRC (2003). Mitigation of HIV/AIDS impacts through Agricultural and rural Development – Success Stories and Future Actions. A workshop report. May 27-29, 2003, HSRC, Pretoria, South Africa.

The Farmer Support Group Taking Action

The Farmer Support Group (FSG), an NGO in sustainable agriculture and natural resource management in KwaZulu-Natal, has woken up to the hardships endured by client communities affected by HIV/AIDS. Two staff members initiated a small pilot in one of the projects to understand how HIV/AIDS impacts on people's livelihood, and to explore what kind of assistance can be provided.

Because the field of HIV/AIDS was completely new terrain for FSG, it was decided to start small and grow bigger. An assessment was conducted to understand the households living conditions, and how shocks and stresses impact on their livelihoods. Two major factors were identified that impact negatively on food security: firstly, decrease in yields from land due to unsustainable farming practices and inappropriate management practices; and secondly, the impact of HIV/AIDS on a household's resources (e.g. loss of income, food reserves, income and savings) which are used to pay for health care and/or funeral costs. These factors were seen to have negative impact on the fair distribution of food and other basic needs of the household.

Changing the approach from working with community groups to working with individual homesteads confronted FSG with a face of poverty not observed before. All households wanted a homestead garden and volunteered to prepare a plot on their homestead, which they fenced off, and prepared for planting. Vegetable seedlings were provided free of charge and the first crop of vegetables could soon be harvested.

The team was faced with requests for assistance in applying for grants for child support, disability, and foster parenting. Although this would normally fall outside their brief, staff felt obliged to assist. The result was an endless hassle with the bureaucracy for signatures, certificates, identity papers and forms. Staff spent much time travelling to and from the village to the clinic, police station, and Departments of Health and Social Welfare. Without their assistance the households would almost certainly not have been able to submit an application.

But of all the achievements, what stands out the most is the transformation that has taken place in people themselves. Their outlook on life is more positive, their confidence is boosted and they feel their life has turned around for the better.

The pilot project has given FSG the confidence to develop a programme on food security in relation to HIV/AIDS, with the aim to move from 'the obvious' to an in-depth understanding and to address the impact of HIV/AIDS in other areas of their work. One of the main challenges is to develop and implement strategies that address the specific needs of HIV/AIDS affected households.

Msinga Partnership on HIV/AIDS and Food Security

Based on the pilot project and the call for proposals of RENEWAL, FSG has launched a new initiative in Msinga (KZN) in collaboration with Sinozwelo[16] (a community managed organisation, initiated by several governmental

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[16] Sinozwelo is one of 23 initiatives in KwaZulu-Natal focusing on HIV/AIDS infected and affected people, in which several governmental departments (i.e. Department of Health, Department of Social Welfare, Department of Agriculture, and Department of Education) have combined efforts according to the integrated national plan.

departments) and the department of Biology and Society of the Vrije Universiteit Amsterdam (the Netherlands) to support HIV/AIDS affected households. The aim is to stimulate discussion among farmer groups of HIV/AIDS affected people - mostly women - on how AIDS impacts on their lives, to discuss and negotiate ways of protecting themselves against HIV and the impact of AIDS, and to achieve food security and well-being at the household level.

The overall aim of the project is to contribute to improved food security and well being of AIDS affected farmers and households in Msinga sub-district by increasing their ability to fight HIV/AIDS.

Approach

The action research project will be carried out in Msinga, one of the four Local Councils in Umzinyathi District (KwaZulu-Natal), an area of 1762 km^2 with an estimated population of 160,000 people. During the past few years, a network of HIV/AIDS services has been developed in this area, including Voluntary Counselling and Testing, a Mother to Child Transmission Programme, Treatment of opportunistic infections, a TB DOT programme, Home Based Care (HBC), a Hospital, ARV treatment (to be developed), a hospice, Sinozwelo, A place of safety, and Social Welfare grants. One of the main organisations to support HIV/AIDS infected and affected people and responsible for the HBC-system in the district is Sinozwelo. In 2003, Sinozwelo started support groups around HIV/AIDS and food security. Health workers helped identify families willing to participate. These groups are distributed over several Traditional Authority areas, vary from five to 60, and consist mainly of female farmers. Although irrigation farming is present in Msinga sub-district, most of the support groups farm in dry land areas where the impact of HIV/AIDS is likely to be worse. Within this project, the FSG works with a selection of these support groups.

A specific participatory methodology was selected for this study - the Interactive Learning and Action (ILA) approach - developed by the Department of Biology and Society of the Vrije Universiteit Amsterdam (VUA) in the Netherlands. This approach does not offer a blueprint, but a set of principles and guidelines to use. It consists of an initial phase in which the current situation is analysed, ideas generated, exchanged, and prioritised; and a phase in which action plans are developed, tested and evaluated in a continuous cycle. In the initial phase, methods and tools such as semi-structured interviews, focus groups, diagramming, visualization techniques and workshops are used. In the phase of planning, testing, monitoring and evaluation, joint experimentation and variants of Farmer Field School-approaches are applied. Also, elements of other methods will be integrated in the approach.

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Ethical Considerations

An important aspect of working on HIV/AIDS is the concern for safety and confidentiality between project members and infected and affected people and families. Working in areas such as agriculture, where information given by respondents seems less sensitive, the ethical aspects of research have often been taken less seriously in practice. Especially for organisations not used to research and ethical guidelines, the following aspects may give some guidance.

- The research takes place in agreement with stakeholders involved. Participants are fully informed about the nature and implications of the research. Confidentiality is respected - to guarantee this, information retrieved by research is codified so that it is not possible for others to retrieve the source of information. All those involved sign a code of conduct on how to deal with sensitive information in the research area.
- The research strives to have no negative side effects on the participants. The research plan will be discussed and agreed upon with the main stakeholders.
- Research findings are fed back to participants for comment and correction. Throughout the action-research, transparency of information and outcomes is guaranteed, so that participants can benefit immediately from innovations that can prevent or mitigate the impact of HIV/AIDS.
- Participation is on a voluntary basis. Participants and support groups can decide at any moment to withdraw from the project.
- Key intellectual contributions will be recognized and respected, as they will be in any resulting publication.

Rob Smetherham Bereavement Service for Children

> …to bring hope and healing through therapeutic play interventions to bereaved, orphaned and vulnerable children in communities affected by death and loss.

Children in our communities experience multiple losses especially due to HIV/AIDS. Play is a child's natural medium of communication and the project transfers creative therapeutic play skills to members of the community so that they may assist their children. The community members trained become able to provide psychosocial support through play, and this strengthens the child's ability to cope with the losses experienced.

Our project aims to grow the number of people who support bereaved children rather than the size of the organisation. Our team is small and direct impact starts small but is strategically aimed at "growing" people in the community and increasing the access to psychosocial support for children in the community. We do so in the following ways:

1. We have a community model that focuses on leaving skills in the community. By the time we exit a community we would like the community to have a range of people who are able to provide:
   - support for individual bereaved children (We offer practical training in how to talk to individual children about death and dying and use basic play skills to support the child's coping);
   - direct care for children through support groups (We train and mentor people to work with groups of bereaved children);
   - awareness presentations to increase the response to bereaved children (We train and mentor people to create greater awareness);
   - support bereaved children in schools (We train people in schools to work with children).
2. We work with and train other organisations or groups that offer assistance and support to communities (for instance home based care, palliative care, and other support) to increase their work with, and support to, children.
3. We are conducting research into a Family Support Model that will provide guidelines for use by various individuals, groups and organisations that offer support to families affected by death, HIV/AIDS and family disintegration.

We enter a community because that community recognizes a need to address the needs of bereaved children. Our relationship with a community has a time limit. Once we exit a community there are several sources or people able to respond to the needs of bereaved children in that community.

Lulu Hlophe of the Rob Smetherham Bereavement Service for Children

The Edendale HIV/AIDS Drop-in-Centre

Mrs Florinah Ngcobo, Centre Manager

Florinah Ngcobo

The Edendale HIV/AIDS Drop-in-Centre is currently under the Nobuhle Project, which is a community-based organization. It has six staff members, two nursing sisters, one administrator, one housekeeper, a sewing tutor and a gardener. Clients get referred to the Centre by the surrounding clinics and hospitals. The Centre has ten beds. Clients are admitted for up to six weeks depending on their condition.

Clients who seek accommodation are mostly those who have been chased away from their homes because of discrimination. Others are starving and others have no one to look after them during the day.

The Centre holds three workshops per annum on basic counselling, home based care programmes, AIDS awareness information, sexually transmitted diseases and TB. These workshops are held to help HIV/AIDS affected families to love and look after their sick people.

The Centre has no visiting doctor and would be happy to own a vehicle to transport the sick people to and from hospital.

Centre for HIV/AIDS Networking (HIVAN): Offering Research and Networking Services to Stakeholders and Communities

Debbie Heustice, HIVAN Project Manager, University of KwaZulu-Natal

Debbie Heustice

The Centre for HIV/AIDS Networking, a unit of the University of KwaZulu-Natal, was established in 2001. HIVAN is externally funded and has Campus HIV/AIDS Support Units on the various campuses of the University. In addition, three satellite research offices are in place at McCord Hospital; Ekhuphileni Clinic, Cato Manor; the uThukela District Child Survival Project in Bergville.

HIVAN is dedicated to multidisciplinary research, networking and, in partnership with other organizations, to targeted intervention in the field of HIV/AIDS. We engage social scientists, their biomedical colleagues and public health practitioners in open inter-disciplinary debate and shared research in the many arenas affected by HIV/AIDS.

HIVAN's partnerships extend its work to include practising clinicians, other health care workers, the public and private sectors, NGOs and CBOs involved in fighting the epidemic in KwaZulu-Natal and beyond.

HIVAN sits at the hub of major activities in ongoing HIV/AIDS research in KZN, and learns from the lessons of ongoing care and treatment in practical settings. Through its various field-based research projects, HIVAN is in close contact with the communities most affected by HIV/AIDS, as well as those directly infected.

HIVAN came to give an overview of their services so as to make them available to stakeholders in both the community and government. These are listed briefly below. For more detailed information go to www.hivan.org.za.

Mission

- initiate high quality multidisciplinary research, mentorship and capacity-building programmes
- facilitate networking and collaboration amongst researchers, trainers, and practitioners
- equip the University of KZN to deal with the effects of the epidemic amongst students and staff.

Website & Database

The HIVAN website is an HIV/AIDS resource hub, with AIDS information, research, news and funding information. It covers KZN and beyond, with 8 500 visitors and 35 000 pages a month. The database includes 779 organisations, as well as individuals. It is available in hardcopy in the KZNCAN directory.

Media

- Sondela Community Newsletter
- Share Sectoral Brief
- Press releases and media commentary
- Coverage about HIVAN, its partners and important initiatives in KZN

Outreach

HIVAN reaches out to the University campus and broader community. They offer peer education, counselling and resources. A two week bi-directional exchange by civil society practitioners in Africa aims to build partnerships and broaden knowledge.

Research

HIVAN research responds to community needs, rural and urban, collaborating with other organisations. Some current research focuses on clinical, psycho-social, domestic and community contexts. They use and offer training in ethnographic research methods. Other research focuses on community-driven models and responses. Their Leaders of Tomorrow Project is researching community-driven strategies for orphans and vulnerable children.

Breakfast Briefing – 18th February 2004

On the morning of the second day, the 18th, PACSA hosted a breakfast briefing for leaders from the Church, Government and civil society. Reverend Sipho Mtetwa opened the briefing with a prayer and Daniela Gennrich welcomed those present. She went on to give an overview of the previous days conference proceedings.

The special guest was introduced by Reverend Sipho Sokhela. Canon Gideon Byamugisha is an HIV positive Anglican priest from Uganda, and has been spreading his message of hope throughout Africa. He has won many awards for his work in HIV and used the money from these to start a trust called the "Friends of Cannon Gideon Foundation". Reverend Sokhela spoke about the time he spent with the Cannon and described his ministry as, "beyond the Church – it is for the world."

The Canon opened his speech by saying he had two pieces of good news: One: that HIV is preventable; and two: that HIV/AIDS is manageable. But, he said, the one piece of bad news is that we cannot wish AIDS away.

"I started my journey with HIV in 1991 when my dear wife died. This was very sudden: she complained of a headache and back pain on the Friday, was diagnosed with pneumonia and I was told to bring her back on Tuesday. On Tuesday she died. So I was rudely introduced. I am not meant to be an AIDS activist, I am meant to be a Theologian"

It was only six months later that her sister told him that his wife had tested positive. "This was devastating – a priest having HIV, a born again Christian!" He tested in 1992 and the test confirmed his worst fears. So teaching theology became secondary and he realised his priority was to teach about HIV.

This presented many challenges because either people did not believe him or judged him because he was a priest that was positive. He subsequently married an HIV positive widower and they have two children. He told us that he had lost 20 kg – from 78 to 58 and that his cd4 count had been miserable. He said that he is able to speak now because of the treatment; his viral load is undetectable; and his CD4 count is almost as someone with no HIV.

He said he was attracted by the name of the place PACSA did its research in – Mpumuza - because in his language, Muza refers to comfort and hugs. He believes that comfort is very important to people who are positive.

His strongest message was about stigma. Included in this is the stigma attached to HIV positive people choosing to have children. He also spoke about self stigma, where people turn in on themselves and are afraid of disclosure.


Canon Gideon Byamugisha

Linked to this was a message about blame. He said that people were all trying to blame it on a certain group, men blaming women, women blaming men, old blaming young and young blaming old, and so on. In order to fight the disease, he said, we need to stop the culture of blame.

He said there was a lot we could learn from Uganda. There, they take a multi-sectoral approach to HIV, with all sectors of society doing what they could to fight it. In Uganda, they have even had senior majors in the army come out about their status.

He ended by saying, "I passed all the exams and then I failed the HIV test – that makes me very sad." But he said that his life and Uganda's success is a testimony to the fact that we can fight HIV.

After Canon Gideon's input, there was some discussion and people enjoyed their breakfast.

The uMsunduzi HIV Strategy

Dr. Julie Dyer

Standing in for the Mayor, the Director of Health in the region, Dr Julie Dyer, shared with participants the municipality's approach and practice around HIV/AIDS.

Background

The municipality realised that the way to success in all its work was through partnership and consultation – and with their HIV/AIDS strategy, this is what they have done. For the council, this strategy belongs to the Msunduzi people, not the municipality.

So What Has This Strategy Involved?

Care for Vulnerable Children including Orphans

This has involved:

- working with the CINDI (Children in Distress) network around orphan and children's issues;
- trying to deal with the problem of birth certificates and welfare grants;
- bringing children and AIDS into the Council's Integrated Development Plan;
- addressing housing needs of children through providing buildings for NGOs - using a survey of child-headed households and their needs (conducted by Thandanani as a basis for a housing summit, which brought together municipal departments, Councillors, NGOs and Provincial departments) to find ways of meeting housing and service delivery needs.

Development of Ward-Based Strategies

This has included:

- establishing Ward AIDS Committees;
- identifying HIV issues affecting each ward and developing plans to address these (these plans could include home based care, education, care of orphans, drop in centres, condom distribution, feeding schemes, formation of support groups, TB support, vegetable growing);
- The committees are met with every two weeks and assisted to complete these plans.

Progress

- 23 Wards are now active;
- these receive support with training and materials, small incentives (for example group payment for conducting community training on AIDS) and with running the committees;
- committees are now being organised into CBOs, with their own bank accounts;
- five wards have found business partners to sponsor some or all of their projects.

What Has Been Achieved So Far

- ➢ there are now 430 active, supported home-based carers caring for 540 patients as well as one drop-in-centre;
- ➢ 3,500 people have been reached in 120 community-run AIDS education sessions, for which the CBOs have been paid;
- ➢ 4000 children have benefited from education through the "creche programme";
- ➢ many people are fed through the weekly soup kitchens;
- ➢ 2000 children have been reached in 16 Christmas parties.

Dr Dyer thanked PACSA for its efforts to bring everyone together and said she looked forward to the outcomes of the conference.

Key Findings of PACSA Research on Churches' Involvement in Poverty Alleviation: A Case Study of the Midlands in KwaZulu-Natal

Presented by *Ms. Nokulunga Sibiya,*
PACSA Poverty and Economic Justice Fieldworker.

Research Conducted by *Mrs Penny Dladla* and Compiled by *Phila Xuza and Thembela Njenga.* Commissioned and Coordinated by *Thembela Njenga, Poverty and Economic Justice Coordinator*

Background

Poverty, huge income inequalities and rising unemployment are central challenges facing South Africans. After coming into power in 1994, the ANC Government sought to deal with these problems through the Reconstruction and Development Programme (RDP). This strategy changed in 1996 with the introduction of GEAR (Growth, Employment and Redistribution) - the macro-economic strategy of South Africa. Though it promised jobs, there have been many job losses, deepening poverty and increasing unemployment for many. Despite attempts by government through initiatives like social grants and public work programmes, the effects of poverty remain distinct, with 22 million people still living below the poverty line - about R354 per adult a month (equivalent to 2002). Poverty is still related to race, gender and urbanization, with 91,1% of the poor being African and 54,4% headed by women. The HIV/AIDS epidemic worsens the situation with between 1500-1600 people being infected daily (South Africa Human Development Report 2003; Medical Research Council 2001; cited in *The Church in an HIV+ World: A Practical Handbook*, edited by D. Gennrich, Pietermaritzburg: Cluster, 2004; cf. e-Praxis, 12 July 2000).

With this background, the task of the Poverty and Economic Justice programme was to educate communities on economic literacy. Our work amongst people living in desperate poverty forced us to confront the question of our response, as an organisation, to poverty. We decided to respond by conducting research to:

- develop an understanding of poverty as experienced by churches;
- find out what churches are doing in response to poverty and the obstacles they face;
- link churches so they can learn from one another;
- explore how PACSA can (together with churches) respond to poverty.

This research took place in the Greater Edendale Area, Sweetwaters and Sobantu. Some of these areas are rural and some semi-rural. 65 churches were interviewed.

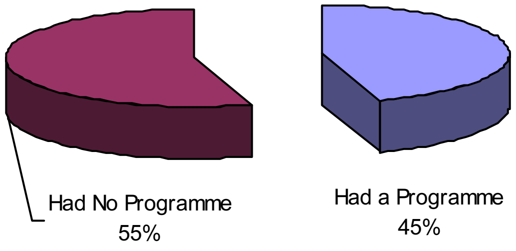
The Churches' Definitions of Poverty

The churches defined poverty in the following ways:

- a lack of income;
- a lack of basic needs to sustain life;
- the lack of skills, knowledge and resources;
- not knowing where one's next meal would come from;
- an attack on human survival as it leads to an increase in diseases.

Initiatives undertaken by the Churches

Poverty Alleviation Initiatives

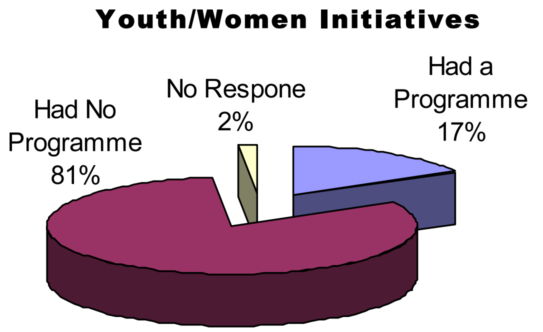


55% of the churches interviewed had no programmes. Of those involved, there were a few instances where the Church, as an institution, was involved. On the whole, however, it was women and young people who were mostly involved. Examples of initiatives were:

- contributions to burial societies and hardship funds
- training programmes
- fundraising
- building projects and
- counselling

Reasons given for non-involvement included lack of skills to raise funds and conduct marketing and a lack of finances, infrastructure and information. Some had started initiatives but these were not sustainable.

Poverty and Economic Justice Programmes involving Women or Youth



Only 17% of the churches had any programmes involving women and youth. These covered social upliftment programmes and economic initiatives.

Social Upliftment Programmes

Social upliftment programmes included teenage education, child-care, home-based care and nutrition schemes for people living with HIV/AIDS.

Economic Initiatives

Economic initiatives included vegetable gardens, sewing, beadwork, baking, craft-making, pottery and sale of fruit and vegetables.

Challenges Experienced

Respondents mentioned the following challenges:

- People were demotivated.
- It was difficult to access support from local authorities.
- There was sometimes fragmentation and internal divisions within the churches.
- Those with hardship funds experienced problems with nonpayment due to unemployment.
- Some thought poverty was not really their problem.
- Others felt it could "wait" so that the churches could deal with their own problems.
- Others felt they didn't have places of worship and therefore could not deal with poverty.

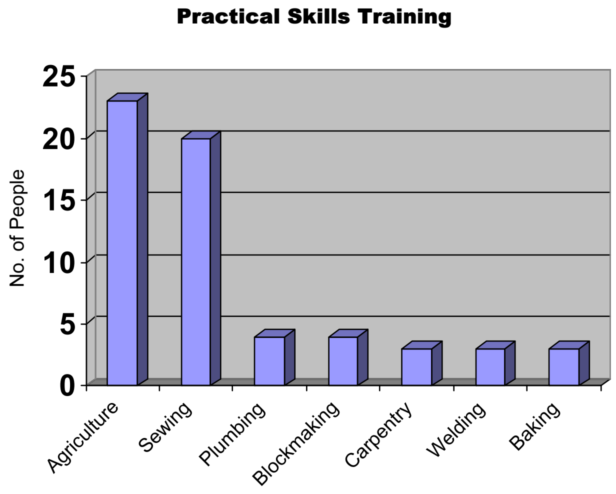
Support Needed

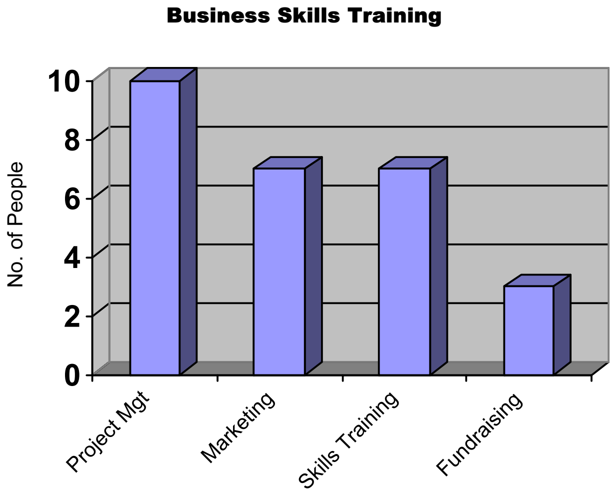
Support needs included:

- skills development and training;
- access to resources, including financial and material resources;
- information on resources available for poverty alleviation.

Skills Development and Training

Skills development and training covered practical and business skills.





Material Resources

These include sewing machines, infrastructure, donations for food and clothing.

Recommendations to the Church Community

- ✞ Church activities on poverty alleviation should be coordinated.
- ✞ Churches need to identify their areas of strengths. This could take the form of a resource assessment.
- ✞ Churches should be mobilised so that resources are shared.
- ✞ Interaction between churches and local government is imperative.

Recommendations to PACSA

- ✞ PACSA should facilitate channels of communication between local government and the Church community; provide information on current poverty alleviation activities including best practices; and conduct further research with more advantaged churches to see how economically poorer and the richer churches can complement each other.

Conclusion

From this study it was clear that the Church consists of people who are unemployed and who live without food and other basic necessities of life. Poor churches have a lot of social capital but lack productive capital which is imperative for a meaningful contribution towards poverty alleviation. Poor churches also lack human capital which is the ability of an individual to work in order to generate income. Although the will is there, it is practically impossible for poor churches from disadvantaged backgrounds to make a meaningful contribution towards poverty alleviation without start-up support and skills on how to set up a project.

A Theological Reflection on the Impact of HIV/AIDS in Our Lives

Bongi Zengele, Institute for the Study of the Bible – University of KwaZulu-Natal

Bongi led the gathering through a Bible study. She explained that she would need everyone present to take part and that she would not simply give an input. For her, this was important in showing us all a different way of working with the Bible.

Bible Study: Matthew 8: 23-27

23: "And when he got the boat, his disciples followed him.'

24: "And behold, there arose a great storm on the sea, so that the boat was being swamped by the waves; but he was asleep.'

25: "And they went and woke him saying, 'Lord, we are perishing."

26: "And he said to them, 'Why are you afraid, o men of little faith?' Then he rose and rebuked the winds and the sea; and there was great calm."

27: "And the men marvelled, saying, 'What sort of man is this, that even winds and sea obey him?'"

Bongi asked delegates to form small groups and discuss the following questions briefly:

- ➢ What is the text about?
- ➢ How does this incident impact on what is happening in my life today?
- ➢ How are we challenged to face our life realities?
- ➢ How does this reading help us to deal with difficulties of living with HIV/AIDS in a positive manner?
- ➢ What are the main five things/involvements we choose to take part in as a way of dealing with HIV/AIDS in the community?

After the sharing, groups held hands and Bongi led the conference in prayer.

A Model for Holistic Intervention in Rebuilding Self-Sufficiency in HIV/AIDS-affected Families

R.L. Kluge and L. Buthelezi

Introduction

The Mpophomeni HIV/AIDS Mission was started towards the end of 1998 as an outreach project of the Hilton Methodist Church. Mpophomeni (meaning ‘waterfall’ in Zulu) is a small township of about 35 000 people near the town of Howick, 120 km west of Durban in the province of KwaZulu-Natal, South Africa. Unemployment levels in the township reach more than 80% and up to twenty-five people a week die from AIDS or AIDS-related causes. Typically the breadwinner in a family succumbs to AIDS, leaving behind families made up of grandmothers and orphans or even child-headed families.

The Mission is funded solely by donations from Churches and individuals, both locally and overseas. Three field workers are employed: an emotional counsellor, a spiritual counsellor and a permaculture teacher. Their contracted work hours range from 16 to 32 hours a week and they are supported by a team of volunteers from the Churches.

The aim of the Project is to help struggling AIDS-affected families to become as self-sufficient as possible in the long-term, by addressing their physical, emotional and spiritual needs and in so doing, build the Kingdom of God in Mpophomeni.

The four goals of the Mission are:

1. to meaningfully improve the long-term physical, emotional and spiritual well-being of the families served by the Project;
2. to make a contribution to the rebuilding of HIV/AIDS ravaged communities through families that have been healed;
3. to develop a practical model - for cost-effective rebuilding of HIV/AIDS-affected families - that may be useful to other groups wanting to do this kind of work;
4. to give a practical demonstration of God’s love by His Spirit through Jesus Christ.

The project is purpose-driven rather than goal-driven.

This input focuses on the third goal – developing a practical and cost effective model that can be used by others.

The Model

The model has five phases: a waiting list; emergency aid to meet the immediate physical needs; an initial rebuilding phase that addresses emotional needs and offers lifestyle and skills training; an advanced rebuilding phase which serves as consolidation; and finally, a maintenance phase. Ideally, the first four phases extend over three months while the last has no time limits.

Step One - the waiting list

Because of financial and practical constraints food can be provided to about fifteen families each week. This means that new clients need to go onto a waiting list. This time is used to seek proof of their HIV status, family details, any other help they are receiving (e.g. from Hospice) and to build up a background picture of the client.

The way in which the Mission works is explained to prospective clients. It is stressed that while the aid of the Mission is not given free and clients are expected to earn what they receive as much as they are able to, the services and resources of the Mission are available to all who are willing to help themselves. Clients are given advice on Government welfare grants and are helped to make applications. Clients are warned that the project shows low tolerance for people who are using alcohol or drugs. (The Mission is not equipped to deal with these problems and our experience has shown that complications caused by such abuse waste precious time that can be better spent in caring for other families who are serious about improving their conditions.) Once clients are clear on these issues and agree with these conditions, an application form is signed.

Mpophomeni HIV/AIDS Mission outreach

Step Two - emergency phase - first two weeks

The client receives a full food ration for a week, food supplements such as e-pap (instant porridge with extra vitamins and minerals) and vitamins and money for electricity. Other necessities such as clothes, bedding, school uniforms and school fees are given if appropriate. Each client is issued a "work book" for recording tasks allocated to them each week and to evaluate these tasks (A = task done; B = task not done satisfactorily; C = task not done). It is important for the self-esteem of clients that they attempt the tasks, unless of course they are too ill to do so. Grant applications often need follow-up and if successful, a bank account must be opened into which the grant can be paid. This is compulsory, not only for the clients' own convenience and safety, (cash is vulnerable to 'disappearing') but also so the Mission can assist clients to learn to manage their resources. The counsellor spends time with clients and their families dealing with some of the emotional impacts of the illness, if this is requested.

Step Three - stabilization phase - weeks 3-6

In this four-week phase, information is shared on a healthy life style, good nutrition, good food preparation, drinking water, exercising and the use of the hot box for cooking to save electricity. One of the priorities for the project is to help HIV/AIDS-affected people generate an income, and to this end, the Mission has established a market for hand-crocheted bags. A client is given a work kit (a hook, cotton, needle, and a pattern for crocheting) and training. Once the client can crochet, an 'order' is placed each week which is recorded in the work book. Crocheters are paid "encouragement money" for their first three bags even if they are not up to standard, and after that they are paid full price for the articles produced.

If a client does not fulfil his or her agreement (such as not doing any crocheting in a week), a discussion is held and consequences are again outlined (such as foregoing weekly visits or even - for repeated lack of commitment - a return to the waiting list).

Spiritual counselling may begin if the client is ready. The client's beliefs are respected regardless of what they may be, although people are encouraged to become active in their Church/religious gathering and to fellowship with other believers of their Church or other religious groupings. While the Christian beliefs of the Mission are not forced on clients and clients are invited to ask or challenge team members about their beliefs, dialogue on spiritual matters is initiated.

Mpophomeni HIV/AIDS Mission outreach

Step Four- rebuilding phase - weeks 7-12

The client is encouraged to start a vegetable garden. The permaculture instructor on the team will initially mark and lay out a small area of 3 x 3m. In time the size of the garden may be increased depending on the enthusiasm of the client. Clients are given instruction in permaculture/organic culture methods and provided with seeds, poles and fencing that they are expected to pay back later when they have generated income from the garden. Should a client lose interest in his or her garden, the fences are taken back so they can be used for another more committed client, as resources like fences are scarce. As a first task, the client digs the holes for poles for fencing. Thereafter, each week, a further task for the garden is agreed on, written in the work book and then evaluated.

Clients are given food according to their commitment to their tasks of crocheting, grant applications and vegetable gardening. If all agreed tasks are completed, a full food ration is received whereas proportionately less of the food ration is given if tasks are not done satisfactorily. For example, should a client not complete any of the tasks, a "C" grade would result in no food being given out. This does not happen very often but it is important to maintain a clear sense of the link between rights and responsibilities - to avoid passive dependence - as this would be counter to the overall goals of the project.

By this stage many clients are receiving grants or generating small amounts of income through their gardening or crocheting. Some clients are inexperienced in handling money while others need some protection from unscrupulous family or other connections. The Mission seeks to help clients understand important financial matters such as drawing up a budget and spending money wisely. Clients are encouraged to save: the Mission provides two thirds of the weekly income in cash while the remainder is recorded as "savings" in a work book. In addition, each week clients may also access 10% of the saved balance as cash. (So, if they have saved R500, they can access R50). The money earned is only for essential living expenses (rent, food, water, electricity, schooling and medical costs) and the money saved is for emergencies, not for luxuries (TV, furniture).

In order to help clients prioritise their expenditure, they have to account for the way they spend their money. The Mission takes the view that the income generated is as a result of a partnership between the project and the clients, and this justifies its involvement in helping clients to spend their money sensibly and appropriately.

Understandably, for many people suffering from HIV/AIDS, peace of mind about arrangements after their death is important. To help ensure that their personal wishes will be carried out, especially where there are children concerned, the Mission assists clients in drawing up a will and in taking out a funeral policy. It is also essential to make sure that the title deeds to clients' homes are registered in their names.


Lindiwe Buthelezi

Step Five - maintenance phase - after about twelve weeks

Ideally, after three months, clients will be physically, emotionally and spiritually strong enough to begin taking care of themselves; there should be a steady income from the grant; and hopefully they have learnt to budget and spend wisely. Clients are encouraged to carry on crocheting and gardening to earn extra money. In order to encourage this self-sufficiency, the weekly food ration stops and clients are now responsible for buying their own food. Importantly, the supportive services of the emotional and spiritual counsellors and the permaculture instructor are still available to clients. As a further encouragement to clients' self-esteem, those who have been helped by the Mission are encouraged to show their appreciation by offering to do up to two hours voluntary service in their own community per week, such as helping newcomers to the project.

Conclusion

Is the Model Working?

Bearing in mind that the model is still being developed, and not forgetting that statistics are not as important as individual lives that have been affected, it is already serving a useful purpose as it provides a structure for carrying out the work and some means of measuring progress.

In terms of the first aim of the Mission i.e. "helping families to become as self-sufficient as possible for the long-term", there are cases where this has been realised. For example, M..., a teenaged AIDS orphan has been associated with the Mission for five years and is keeping himself at school from money from his gardening work and his own vegetable garden. B.... cared for her son until he died of AIDS and her only income for the past three years has been from crocheting bags. This will keep her going until she qualifies for a pension in three years' time.

The second aim of the Mission; "addressing the short and long-term physical, emotional and spiritual needs" has also been realised.

Physical Improvements

Short-term physical benefits are obvious, such as the remarkable physical recovery clients make when they simply have good nutrition. There has been varied success with the long-term physical improvements. For example, a young single mother , O..., has now been well enough to run a small day care centre for preschoolers for the past two years. A mother and grandmother, E...., whose daughter died of AIDS, was begging from neighbours four years ago but now has been earning up to R200 a week, enough to keep her children and grandchildren going. On the down side, some clients prefer to go their own way once receiving a grant, which seems to invariably lead to wasting their money and a reversion to poverty.

Emotional Needs

Much success has been achieved here. In the short-term, the mere relief from anxiety over pressing material needs leads immediately to renewed hope. The longer-term impact is more difficult to assess, but notwithstanding their HIV positive status and everything that goes with that, many clients remain surprisingly positive and happy. For example, O……… a young single mother who is now running a crèche and who was mentioned earlier, was experiencing extreme physical and emotional lows two years ago. Her improved emotional strength has enabled her to access a grant, live in her own house and start a business.

Spiritual Benefits

There have been some successes, especially where clients have responded to the Christian gospel offering forgiveness and hope of life after death For example, N........ a truck driver was already bedridden when the Mission met him but he responded to the gospel and found peace before he passed away. There have been many successes, because clients faced with the real prospect of imminent death are very open to talking about spiritual matters and making their peace with God as well as those close to them.

Some of the Major Obstacles Frustrating this Model

Alcohol abuse is a major problem because it is widespread and intractable and complicates all other issues. It also inhibits clients' ability to engage effectively with the income generating tasks on which the Mission is based. Such clients are prone to wasting their grants by, for example, buying junk food or signing hire-purchase agreements for luxuries with unscrupulous furniture dealers. Alcohol abuse is also a waste of the scant resources many clients have.

The model is still in an ongoing process of development, informed by our experiences in running the Mission, and any suggestions and comments would be welcomed.

Acknowledgements

We gratefully acknowledge all intercessors and donors who support the Mission, particularly our partner, the Atonement Lutheran Church in Missoula, Montana, U.S.A. and Leanne Long for editing the manuscript.

Left:
Poverty in Edendale, outside Pietermaritzburg.

Below:
Imbalenhle Clinic, one of the institutions fighting this poverty.

Notes from the Field

Amandla Awethu: a Rural South African Case-Study of Raising Awareness about HIV

***Jean H Davidson*[1] *& Richard J Haines*[2]**

Background to the Case-Study

St Joseph's Catholic Mission is 25 kilometres north west of Ladysmith in rural KwaZulu-Natal, South Africa. There are about 700 people living on the Mission properties. In KwaZulu-Natal 32,5 percent of the population is HIV positive. Put very simply, this means that one in every three people is already infected with the HI virus (United Nations 2001).

The Mandla Project is a community initiative that arose out of a rural development gardening project for elderly women living on the Mission. The women grow organic vegetables in four door-sized, raised gardens at their homesteads. The gardeners meet once a month to learn about organic gardening; bottling, drying and preserving food; basic nutrition and cooking; and basic project planning, management and financial skills. The project started in January 2000 and is funded by a private donor.

The gardeners have elected their own committee and are drawing up a constitution. They have opened a bank account for the money they themselves have raised. Fund raising is an on-going process to ensure the longer-term sustainability of the project.

The gardening project aims to help elderly people grow enough vegetables for a family of six throughout the year. Elderly women were chosen because they are the people who have to care for children orphaned by HIV/AIDS, and for unemployed youths. All of the women are volunteers and not paid.

When the project started it did not include HIV/AIDS awareness training because others were doing it. However, in 2001 they decided to include it because of the terrible impact HIV was having on the community - there had been on average three burials each month at the Mission. A walk through the graveyard is a reminder that, whilst the existence of the virus is often denied, its silent spread of terminal, tragic spin-offs is very real. All ages are infected and affected. Also, they were concerned that very little HIV awareness training or home based care support was reaching the Mission community. Early in 2001 the AIDS office run by the Ladysmith Municipality was closed for several months.

Mandla: The Reason and Vision for the Project

In July 2001 the project's field team visited a family living in a far out part of the Mission. Mama Khumalo,[3] who is a member of the gardening group, insisted that we meet her son, who had AIDS. His name was Mandla.[4] She explained that the hospital had told her son that he should go home as nothing more could be done for him. Three days later Mr. and Mrs Khumalo buried their son.

In the next three weeks the project team consulted doctors, dentists, dieticians and community workers, and put together a box of basic ingredients that would help to nurse people with HIV/AIDS related symptoms. These included Jik (bleach); a pair of thick, heavy-duty re-usable rubber gloves; instructions (in pictures) of how to make re-hydration salt and sugar solution; bicarbonate of soda for cleaning teeth and washing the mouth of a patient with oral thrush; ready mixed antiseptic solution; cotton wool; gauze dressings; calamine lotion for skin rashes; camphor cream for bed sores and to relieve chest pain; transpore dressing tape; soap; aspirin and booklets on home based care and coping with HIV/AIDS written in Zulu by Doctors for Life and Soul City. Each box costs R50 (Fifty Rands).[5] As there had also been cholera deaths in the district the box included information on this disease.

On the next visit to the Khumalo family the field team listened to their grief and their concern about their son's two orphaned children. We asked if the items in the box could have relieved some of Mandla's pain. Mr. Khumalo explained that the box would have helped, but that their son had died of an AIDS-related chest infection. *'Yes, then his death would not have been for nothing. Through the box we will remember him and*

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2. Chair: Sociology; Head: Development Studies Group, University of Port Elizabeth
3. The surnames used in this article have been changed.
4. *The Zulu word* – mandla *means mighty, strong, and powerful.*
5. The American dollar to South African rand rate of exchange at the time of writing this article was $1=R8-34.

one day we hope that there will be a cure for AIDS' (Mr Khumalo 2001: personal communication).

The Mandla Project

The beginning of the Mandla Project involved a number of people: the Anglican Archdeaconry in Ladysmith; two local medical doctors originally from Uganda with work experience in community health and HIV/AIDS related issues; retired nursing staff involved in home care; and lay leaders. In January 2001 the South African Catholic Bishops' Conference (SACBC) donated R4000 to the Mandla Project, the St Joseph's Gardening Project donated R1235, and a further R3395 was raised by members of the project.

Jean Davidson demonstrating the stability of the toilet seat

The project attempted to deal with three main practical gaps:

- the lack of HIV/AIDS information in Zulu;
- the lack of easy-to-use awareness raising training materials in Zulu and English for use in rural and urban communities, amongst all age groups and literacy levels;
- the need for basic first aid materials for home based care.

The first part of the Mandla pilot project plan had five objectives:

- to design and make two sets of training materials in English and Zulu which contain the facts about how the HI virus is transmitted, choices of sexual behaviour and how to care for people who are HIV positive;
- to compile a liturgical response for use in parishes on International AIDS Day 2001;
- to draw up a list of local resources, people, addresses and telephone details;
- to make 24 basic first aid boxes for home based care that can be distributed through the St Joseph's Catholic Mission structures;
- to make two Jesse trees[6] for sale overseas to generate seed funding for future phases of the Mandla Project.

During the three month period of the pilot project 1000 brochures and 50 posters from the Department of Health, 750 Soul City comics, 15 Soul City flip chart posters, 20 copies of the AIDS letter game and 30 SWAG poster series were distributed.

At each workshop a list of participants was compiled and this information was circulated. In addition, two sets of resource boxes were made up containing seven videos, (including the Strategies of Hope case studies), information from the Department of Health in English and Zulu and a booklet on home based care.

The gardeners at St Joseph's Catholic Mission helped to pack and distribute 24 Mandla boxes. Subsequently, using the funds raised locally, a further 26 boxes were put together and given to families caring for people with AIDS.

Lessons from Experience

People participated actively in the workshops and enjoyed the interactive nature of the AIDS Letter Game and SWAG materials. Workshop participants of all ages and backgrounds could identify easily with the materials and methodology used and this brought about personal responses to practical, real experiences and provided more than an intellectual learning opportunity. The

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[6] A Jesse tree is a Christian icon of a tree decorated with the symbols mentioned in the Old and New Testament scriptures for the period of Advent and Christmas.

Mandla Project encouraged group interaction and networking. At both workshops participants met people from other communities and projects, particularly the Options Centre and the uMngeni AIDS Centre (uMAC). Whilst the Mandla Project was a pilot initiative, attempts were made to encourage continuity in the longer term. Workshop participants and project beneficiaries are now aware of organisations and resources in the province that they can approach for assistance.

The feedback on the Mandla box was very positive. People are now less afraid of touching and looking after people with AIDS. It is possible to have the Mandla boxes refilled by obtaining items from the nearest Government clinics free of charge. This can be done as long as the patient is registered at the clinic. Mothers and grandmothers are asking questions about the transmission of the HI virus and are keen to learn about practical issues such as drawing up a will, coping with the stress of caring for someone living with AIDS and basic home remedies which can alleviate symptoms.

Concluding Remarks: quo vadis?

Based on the feedback from the first phase of the Mandla Project three particular issues need to be addressed in a second pilot phase of the project:

- Information in Zulu and interactive training materials need to be distributed wider than St Joseph's Catholic Mission. Whilst the Soul City comics are available in Zulu their distribution to rural areas is limited. The layout and presentation of the comics appeal to all ages, especially the youth. The training package put together in the pilot phase of the Mandla Project was well received and cost effective. The workshop participants are willing to share their knowledge with people living in other areas, and it is on this enthusiasm that the second phase of the project needs to be built.
- Mandla boxes met an existing need and more boxes need to be made up and distributed.
- Out of the first pilot phase it became evident that few people know or seem to be able to apply for the relevant Government grants. In some instances this is because children do not have birth certificates, or do not have the details about their parents' identity numbers and death certificates. It would seem valuable to explore proactive ways of how families at risk can get duplicate certified copies of the relevant documents now. This should not be an expensive exercise and could well be a service which local lawyers, accountants, clergy or Rotary and Lions Clubs can offer. In addition, a user-friendly step-by-step pictorial English/Zulu handout needs to be compiled explaining how and where to apply for a grant, and who is eligible.

The Mandla pilot project is a simple, cost effective and practical community initiative that can be easily replicated in adjacent areas. In conjunction with the St Joseph's organic gardening project it addresses the two top world health risks: a lack of food and education about the effects of unsafe sex (Clarke 2002). An exciting and important component of the Mandla Project is that it evolved as a community initiative.

Since the completion of Phase One the gardeners have, through a second fund raising initiative of their own, raised a further R2000 which will be used to buy first aid materials and make up more Mandla boxes.

Can this simple project give practical tools to ordinary, rural people in their struggle against the HIV/ AIDS pandemic? Let's hope that soon the liberation struggle slogan Amandla awethu meaning *Power to the people* will be a reality in the fight against this terrible virus, which exacerbates hunger and poverty.

Lessons for Churches from the Mpumuza Women

By Daniela Gennrich, Mary Moleko and Lindiwe Xaba

In this input, the presenters focused specifically on how the Church was perceived by those living with HIV that participated in the research project reported on in full on Day One of the conference. This aspect of the research compares the faith responses of the 30 women from disadvantaged background with those in the sample of ten who are employed and more highly educated, as well as with the ten men who are also from disadvantaged backgrounds.

What Helps People Who are Positive to Survive?

The women said that support was the most important factor in their survival. This can come from various sources:

- God was the most important source for the women regardless of background, but not the men; (even those women who trusted no one were often able to trust God);
- families;
- HIV support groups
- professionals
- the local Church, but for the poorer women this was for most of them only "as long as they don't know my status"!

All the women said they received support from family, colleagues and the Church (and some at work), but those from the poorer communities received less support. The men found their main source of support was their families.

The Mpumuza women have managed against almost impossible conditions, in many cases it seems through sheer guts. Their faith in God and their need to be there for their children were their main reasons for survival.

The men felt it was a battle to cope, despite the fact that most of them had supportive partners and family members. There was, on the other hand, an indication from men that they did not have faith in God. Only one was actively involved in his Church.

Links

- The research found a link between the degree of illness and ability to cope (in other words, the more sick a person felt, the harder it was to cope)
- It also found a link between educational level and the ability to cope (as discussed further below);

What support structures helped the different groups cope?

Mpumuza Women	Mpumuza Men	PMB Women
Church? 24 of the 30 11 of the 30 felt supported, but only three disclosed status and one was rejected and left	Two of the ten attended as adults, although all ten were baptised as babies. (nervous for Church members to know their status)	ten of the ten (nine of the ten disclosed their status to their Church; all nine felt supported).
Church group ? One women's group member	One men's group member (chair) – felt supported by the priest but did not disclose to members of the congregation	Unclear
HIV Support Group? Eight of the 30; after the first workshop, ten; and now an additional 12 (started own group)	three of the ten	Six of the ten (two have started their own groups – one in the Church)

Disclosure to the Church

It was disturbing that so many of the more disadvantaged people were unable to disclose their status in their Church. This was especially noticeable among the women, in that so many did still go to Church.

Some of their reasons for this were:

- they felt the Church members and clergy were not trustworthy, although they felt God could still be trusted;
- they feared being excluded and isolated by virtue of their HIV status as a result of stigma;
- they found some of the teachings in the Church to be hurtful and a person to be judged to be bad if they were HIV positive;
- because of neglect:
  - "The Church only supports you when dying or dead, but when you are still alive, when you really need them, they are nowhere to be seen"
  - Some families refuse entry to Church groups to pray when one of their members is sick, for fear that it means they must be dying!

What was most interesting was the difference between the two samples of women:

90% of the more educated, more financially independent women disclosed, and 100% of these were embraced (as opposed to 30% of the poorer, less educated women). Why is this so? The following are some possible explanations:

- they are able to take more risks, perhaps because they have less to lose if they are rejected;
- they have more social (and economic) power, and perhaps as a result, they encounter less stigma;
- they are better able to articulate their situation and be heard.

This led the researchers to ask the following probing question, which was discussed in the plenary after the paper, but to which no clear answer was found:

Are the fears of Mpumuza women and men that the Church will reject them valid, or is it self-judgment or self-stigmatisation?

In other words, could it be that the less advantaged women have so internalized the teachings that judge women as inferior, or people living with HIV/AIDS as sinful and deserving of punishment or even exclusion, that they are not prepared to risk finding out if this is really how the Church would see them? Or do the Churches really still put forward such teachings?

This question points to the need for Churches to work extra hard, not only to avoid negative teachings about who God is and how s/he might relate to women and/or to people living with HIV/AIDS, but to openly counter negative and destructive teachings by teaching the opposite, thereby reassuring women and those with HIV/AIDS of God's love (and the love of the Church) for them.

Research participants and the researchers at an interim reportback workshop, at St. Martin's Church, Edendale, May 2003

Fundamental Coping: Spirituality and Strength of Mpumuza Women

Although many of the poorer women expressed an inability to trust their Churches, there was a strong sense of a deep spirituality and a struggling with God in making sense of their lives. Here are some of the things Mpumuza women shared:

Where is God?

> "It helps to know God is here."
>
> "God is not outside somewhere, but within me" and "I am learning to wait for God."

How does God see me?

> "God doesn't judge, although the world does (Jesus gives a second chance)"
>
> "All of us are sinners – only God is prefect."

What helps me keep going?

> "My faith"
>
> "Accepting my situation, not fighting it."
>
> "Forming healthy relationships with other PLWA's"

Organisational Support, Church and HIV Support Groups

Issues around Prayer

The question of prayer is an important one that the women have grappled with. Some important insights from these discussions emerged.

Not being able to pray was seen as lack of faith and a sin, and there was no sense that it was okay to battle with prayer when under extreme stress such as that of living with HIV and/or AIDS. The main theme that emerged from these discussions was that people felt unworthy and confused:

> "I often put all my clothes ready the night before, but come the morning, I find I have not gone to Church again! I don't know why!?"
>
> "I often try to pray, but can't get the words out."

And sometimes overtly rejected:

> "My pastor prayed regularly, laying on hands and very warm. I felt I could trust him, and disclosed my HIV status. He has never, ever touched me since, even to shake my hand in greeting, and rarely comes to pray. I no longer go to that Church."

Conclusion

We (each of us as a part of the Church) need to change as a Church before we can impact on the HIV/AIDS epidemic significantly. There needs to be an openness to evaluate ourselves before God. Some experiences of the Church expressed by the women have been:

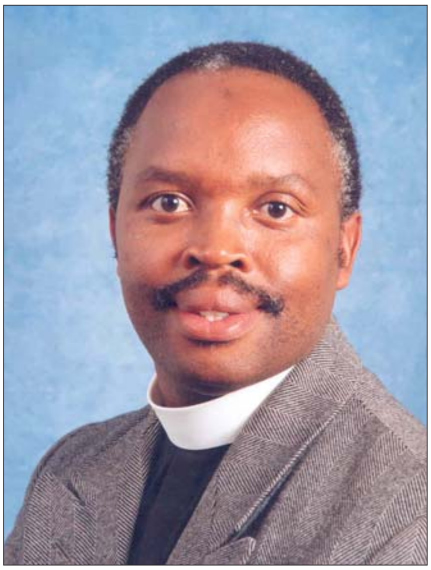
- ✞ judgmentalism or exclusion;
- ✞ negligence when people are chronically ill;
- ✞ buying into stigma and denial by (perhaps indirectly) making women living with HIV feel unaccepted, unsupported and making them believe it is unsafe to disclose.

We need to learn to "do Church differently" and we need to hear the voices of those who are most marginalised in our Churches in order to understand what God is calling us to.

Accepting the Challenge to Live our Theology: A Case Study of J. L. Zwane Memorial Church, Gugulethu, Cape Town

By Reverend Spiwo Xapile

In this presentation, Reverend Xapile, minister of the JL Zwane Memorial Church in Guguletu, Cape Town, shared with us his journey in re-thinking his theology in order to respond in a real way to the HIV/AIDS epidemic.



Reverend Spiwo Xapile

Getting Involved in the AIDS Ministry

It all started when I began wondering what was happening to my congregation. When your congregation is dying, you really have to face that! After all, the congregation is the minister's livelihood and purpose. Without them, what would we do? So to tell the truth, there was a measure of self-interest in deciding to tackle HIV/AIDS head-on.

But there was something else, something deeper. It was the people closest to me, my brothers and sisters in Christ, my friends, my nearest and dearest, that were dying. This was not happening outside, but inside my Church. I began to realize that if I did not respond I would be contributing, by my silence and inaction, to the disaster that was striking down my community before my very eyes.

Knowing Where to Start

Actually, I began to realize that I knew nothing, really, and my theological training was not adequate to help me understand what was happening or what God expected of me.

So began a commitment to listening to people living with HIV/AIDS, and reflecting on their stories in the light of my theological understanding. If one is to understand the struggle of the oppressed one must listen to the oppressed. To understand feminist or womanist theology one must allow women who are oppressed to speak and engage with theology themselves. Unfortunately we are not very good at listening as a Church. In fact, we sometimes choose not to hear what bothers our neighbour for the simple reason that we are not prepared to do anything about it, or are perhaps afraid they will demand too much.

I made the most difficult, yet life-changing, decision about 4 years ago. I invited Christo Greyling from World Vision to use the sermon slot to share about his life as a person living with HIV/AIDS. The response was amazing. A few people came forward and spoke to him (through a translator) about their status and their struggles. I decided then to invite PLWA's to speak to the congregation every Sunday for 15 minutes before the sermon, on anything they wanted to share with the members of the Church. At first, Church people were reluctant to do this. And I decided to open this invitation to everyone, not only Christians. An appropriate chorus like "never give up" would be sung before anyone spoke.

The Impact of Speaking in Church

I must admit, it was probably more scary for me than those standing up in front of several hundred people! Sometimes I wanted to crawl under the pulpit and hide, because the kinds of things that were talked about openly were taboo in our Church, and even in society, and the language they sometimes used made people squirm! I am sure this has never happened in a Church before! I was afraid people would complain and refuse to contribute their tithe. In fact, it has actually happened to me, so I don't blame other pastors for not taking this risk!

Anyone who has ever listened to people living with HIV/AIDS before will have a clear idea of what the congregation has been going through every Sunday for over four years now. There is no better way to sensitize members on HIV/AIDS issues. Allowing people to speak creates and provides a climate of acceptance, love and commitment to doing something about HIV/AIDS. At first people would laugh at a person sharing their story, and that was terrible. But no one laughs today.

People are so moved. Sometimes there has not been a single dry eye in Church. We have listened to stories of lives torn apart, of rejection of individuals by loved ones, of Christian families going to Church on a Sunday morning having locked up someone living with HIV/AIDS in their backyard without food and water.. We have also listened to wonderful moments of reconciliation between husband and wife, parent and child, partners and so on. We have, as a family - the JL Zwane Memorial Church - cried and laughed together and searched for better ways of making a difference. As this process continues, issues around denial, judgmentalism, stigma and breaking the silence are addressed.

Getting the Congregation Involved

Sometimes the talk is in the form of an interview, especially when someone is overwhelmed and cannot speak well. We sometimes allow people to ask questions. This becomes a wonderful opportunity to learn from one another. The last question that is usually asked is what the person speaking would like to see the congregation doing in response to the challenge. We have listened to many suggestions and this is what we think has put our Church in the forefront of responding to HIV/AIDS.

What is interesting is that most often the things people ask from the congregation are not to do with money or things, although when in deep crisis people do ask for help with food. Mostly, their main need is to be loved, accepted and taken care of. Many say they are dying of isolation and loneliness. They want to matter, to be somebody, to be taken seriously. Sometimes they ask for help with relationships in their family. The Church has an important reconciliatory role to play, because people lose each other through HIV/AIDS. Emergency help asked for is usually something individuals in the congregation can respond to. I have often witnessed people standing around the one who shared during the service, offering something out of their cupboards. In this way one is really allowing the whole congregation to do theology – to ask “What would Jesus have done? What is He asking me to do now?”

But sometimes people really cannot respond, because they simply don’t have the resources. That is also alright. Sometimes it is better to know what others need, and to struggle to find a way to help them together. Even if one of us cannot meet the need, maybe we can do it together. That is also doing theology.

The Power of Listening

It’s been quite humbling for me as a minister. When I preach, people shuffle around, even chat sometimes. But during the AIDS sharing time, you can hear a pin drop! I think this is because we are introducing something not usually talked about in Church. These experiences keep the whole congregation talking. A number of our members have come to me to say it has become easier for them to talk about HIV/AIDS issues with their families as they would start the conversation by saying “did you hear that?” People have told me that this has made it easier to break the silence at home too, and more parents have been talking with their children, and children with their parents. In fact, one of our oldest members, who is 73, came to me the other day and told me how his family had called him, as the most senior elder, to a meeting. A young girl in their family had just been diagnosed with HIV, and the family needed guidance from the elders about how to address this. He was able to offer wisdom. He told them that she didn’t ask for this - nobody deserves HIV/AIDS - and advised them to support her. And so, he was able to help the family avoid a lot of conflict.

This, of course, means that parents started encouraging their children to attend Church services. As a congregation we had to make sure that HIV/AIDS education is not seen as a Church responsibility. Parents had to take it up with their children at home. For this to happen, we had to make sure that we talked about it in all our Church organizations such as Women’s groups, Bible study groups, Sunday School, Youth, Girls Christian Association and Sport’s ministry. These groups are key to informing, motivating and guiding others in the Church to make appropriate decisions regarding responding to HIV/AIDS. They usually reflect together on the theological / ethical / cultural issues raised by HIV/AIDS and raise questions on how the Church could be actively involved in challenging some practices that make prevention and care difficult. Our emphasis is on doing something not just talking about it.

Organising Activities

Doing something means planning and implementing programmes of response. It involves identifying people with knowledge, skills, commitment (the heart) and experience necessary to respond. This means that ministers or pastors do not necessarily have to be experts but act as goal keepers to help get things done. We have economic empowerment projects, education programmes and support programmes. But the most important is probably the HIV support group.

We have strong support groups of people infected and affected by the HIV/AIDS epidemic. These groups meet every Tuesday. The success of our initiatives is in part due to ideas generated in these groups. Members usually help brainstorm and come up with suggestions that would shape a number of programmes, including events such as World AIDS Day. They sometimes decide who should speak in Church as they are usually the first to listen to stories. The support groups are a powerful way of learning to cope with living with HIV/

J. L. Zwane Memorial Church, Gugulethu, Cape Town

AIDS. Listening to others share their experience helps those newly diagnosed members find ways of coping with their status and/or their illness.

The Meaning of Listening

We have learnt that we can’t speak for people living with HIV/AIDS. They must speak for themselves. I must admit that this is quite a learning experience for a Church – we are not used to being told by outsiders what to do!

But actually, I think LISTENING is the key. Everything we do must start with listening to those we say we want to minister to.

An example of how we learnt this is something that happened in our youth programme. After running what we thought was a successful programme, we looked back and counted 8 teenage pregnancies among the girls in our groups! We had to ask ourselves: “What are we doing wrong? What is wrong with our message?” So we decided to go back to the drawing board and listen. We called in those 8 girls and asked what was missing from the programme. We learnt a lot from them. Perhaps the two most important things that came out were these: Firstly, we cannot just teach about responsible sexual behaviour, abstaining from sex and/or at least using condoms, without considering what it’s like to be a young girl living in poverty and in a society which teaches them not to argue with men. We had not taken into account their need for assertiveness skills, nor had we taken account of the need to address, with the boys, the assumption that they had the right to take a girl without hearing what she wanted. We had to teach more about mutuality in relationships. Secondly, we had to ask ourselves: “What do you say to people who are very poor who tell you that they had to give a man what he wanted so that they could get some money?” The need to teach negotiation skills is essential. This can also be done by inviting people from other disciplines and NGOs outside the Church.

Another wake-up call came when we began trying to work with men. The men’s group was started by a doctor, Dr Kwezi Matoti, a member of the congregation, and we linked with an organization for men from Uganda. But it didn’t work well. Men just didn’t seem interested. We do have quite a number of men in the support group now, but somehow it didn’t work to take issues to them as men only. I am not sure why. I really don’t know the answer yet, except to say that perhaps it is only once they are in a crisis that men are prepared to join such groups.

I have worked in this Church in the community of Guguletu for 14 years, since 1989. We have 1 300 members, and if you count those who come along but aren’t members, it is about 2 000. Since I started I have married only 13 couples, but I have baptized over 1000 babies! Once again, it meant I had to listen to people’s lives, and think about why. I have come to the conclusion that I am working in a congregation of secondary families! This is because of the migrant labour system, and simply that many men move to Cape Town from the rural areas to try to find work. They often leave behind their primary families, and come alone to a city where they know no one, and have no extended family. They are lonely, and soon they begin to form new relationships with women. They in turn have children, and a whole new informal ‘secondary’ family grows. This has been going on for a long time, and many of the youth today have grown up in families that were unstable throughout their lives. So they don’t commit to marriage as they grow up, because it is a foreign concept to them. They have had no role models of a stable family.

We are dealing with a wounded nation. People have a number of partners, and do not understand the nature of marriage in practice (although as Churches we preach about it). So what do we do? Bury our heads and pretend all is fine? It is not fine. Lives are lost! In thousands! We have to go back to listening, and listening again. Our theology, our ministry, has to be based on an understanding of the lived experiences of our people, not some sort of ideal theoretical ‘good’. The big question is – once we have listened, how do we respond? This is the ongoing challenge.

The Issue of Condoms

My position on condoms is not popular among some friends. But it is based on a theology that I believe is exemplified by Jesus Christ Himself. Throughout His ministry, Jesus gave people choice. Although He was very clear about what was expected He never forced people, but invited whoever wanted to follow to do so. Some were able to respond, such as those who became His disciples. Others did not. And so, in our Church, we offer teaching about self-respect and life-giving relationships based on mutual respect. But we also recognize that life is not straightforward, and so we make condoms available. What is amazing is that they get finished. Through contacts, we are now also able to make available the female condom, because this helps women to protect themselves without having to depend on their partner's agreement. Our people are dying. We are losing people we love and care for. We know condoms are not 100% safe but are committed to reducing the spread of the virus. Canon Gideon Byamugisha helped me to sort out my thinking about condoms. He is very clear that condoms are important for all - including married couples - and they are not just a license for promiscuity, but a sensible tool to reduce the risk of spreading HIV in a society that puts all kinds of pressures on people to engage in sex, whether it is their choice or not.

Men, especially men who have been displaced from their families, often go to Church looking for family. But what do they get if they are HIV+, or if they have multiple sexual partners? Judgment, and a sense that they don't belong there - that this is not a family after all. And so they continue their quest for a family and may end up setting up a secondary family, or just drifting from woman to woman - which is exactly what the traditional Church is judging. And so one could say that the cycle of HIV/AIDS is perpetuated by the Church's attitude.

The Importance of Partnerships

We have, in recognition of the global nature of HIV/AIDS, started partnerships nationally and internationally. This has given me more freedom to take risks as it has meant that, as a minister, I am less dependent on members' contributions. I believe that such partnerships between Churches that are more advantaged and those most in need are essential. This is because the Churches most affected by HIV/AIDS are also those Churches with the least resources, like ours. I have noticed that more and more families are no longer paying their tithes, not because they are angry with the HIV/AIDS ministry – far from it – but because they are getting deeper and deeper into debt as a result of increasing health care costs for members as well as multiple funerals. In fact, without our brothers and sisters in Christ overseas, much of what we do would have been impossible.

The aim is mutual empowerment with knowledge, attitudes and skills to make informed, compassionate and effective responses to HIV/AIDS at all levels. But these partnerships can be made even with a local butchery, Street Youth Group, local business people or another Church. We have a number of these networks that respond with us.

- Our contact with other Churches involves encouraging visits to Guguletu and to other parts of the world. We have taken groups of doctors, nurses, social workers, care givers and people involved in this type of ministry to different centres in other countries and around South Africa just to learn and bring back knowledge and information.
- Our hospice programme involves responding in partnership with St Luke's Hospice. We could not do it alone. We needed a partner with a long history of involvement in palliative care.
- We have a good relationship with the local clinic, so we can easily refer people to them for testing and for ongoing care. In turn, they let us know when a person needs more support at home, and

our home-based carers make sure that s/he is well-cared for.

- We joined forces with the University of Stellenbosch, with the main aim of engaging institutions of higher learning in a process of planning, implementing and testing practical solutions related to HIV/AIDS prevention, treatment and support.
- We have worked very closely with the Treatment Action Campaign (TAC) and continued to encourage members to lobby Government around a number of issues from MTCT to ARV's.

Without partnering with other Churches and organizations nothing meaningful can really happen as we would be too inwardly focused and would really not be in a position to respond to the needs people with HIV/AIDS express. Then we would just be listening to their stories - which is helpful - but wouldn't really change anything. It was overseas Churches that helped us defeat apartheid, and I believe we can count on them to help us defeat HIV/AIDS too.

But another important element is using the professional people within the Church – the nurses, social workers, lawyers, business people. Those that are retired tend to have more time, but others also offer their services when they can. This is important, because we need qualified people as well as those who offer up their time and themselves to do the work. We could not do without one or the other.

At the beginning we had so much opposition, but now 95% of the membership supports the HIV/AIDS ministry. This is just a brief overview of what we are doing. This and much more can be done. Our greatest resource is our people, and yet people are usually the frozen assets of the Church.

Opposition from Others

It has not been an easy journey. One would expect criticism, and we got it. But I was not prepared for the force of it, also in my own life. I had expected to be criticized for letting HIV positive people into our Church, especially letting outsiders living with HIV/AIDS come and speak to our people. I was prepared for the inevitable criticism that we were condoning promiscuity by openly and without judgment accepting people with HIV/AIDS. (A neighbouring Church goes so far as to institute disciplinary hearings when they discover a member is HIV positive!) But what I was not prepared for was that I would become the target. I became promiscuous myself, in the eyes of the people. I personified every evil associated with HIV/AIDS and stigma. Stories abound about how I am dying of AIDS myself, and how I am developing this ministry simply to justify my own condemnation. And what was worse for some people was my association with TAC. People feel so threatened by HIV/AIDS because it is linked to sex, and they cannot imagine that a minister would dabble in such taboo things unless there was something fishy going on!

This has led me into a deep crisis. It has brought me face to face with my own sinful humanity, as I have had to ask myself: "Why is it that we too often have a need to be seen as good, as righteous to the extent of refusing to be identified with 'the sinners'? Why does it hurt so much to be judged so viciously?" If we know that we are fulfilling the Gospel calling – to reach out to the poor and the marginalized – we should not bother

I can really understand why most ministers stay aloof and avoid getting their hands dirty. I met another minister at SACLA conference 2003. I invited him to come and stay with us at JL Zwane for a month, because I was so disturbed by what he was saying: "I would never employ a disabled person in my Church, so certainly not an HIV positive one". On his last day he came to me to make a confession. He had avoided getting involved in HIV/AIDS ministry because of the challenge it presented to him theologically, He had often healed the sick in Jesus' Name, but had never had success with HIV/AIDS. It seemed to contradict everything he had believed about healing and it threatened his good name as a healer! If he admitted he could not heal a disabled person by employing one, his whole ministry would be at stake. So he could not accept that he might be called to serve a person living or dying with HIV/AIDS as it contradicted what he preached, And what was he to do when his ministry lacked credibility because "I could not get them healed?"

Doing What Jesus Would Have Done

It is becoming easier to bear. There is no way that we can sacrifice people to the altar of HIV/AIDS when we can do something. I realized when I started this that I was taking risks, and there have been many times that I have regretted going down this road! But there is no turning back, and I know that we are doing what Jesus would have done. And that is enough. Witnessing the healing that is coming about in people's lives, knowing that people receive the compassion of Jesus through our ministry at JL Zwane Memorial Church, is more than enough to keep me going, keep me taking risks, keep me growing. The support I receive from brothers and sisters in and outside South Africa keeps me going.

Springs of Hope Support Group Project: People Living with HIV Reaching Out to Others Through the Love of Christ

By Anne Ntombela and Mbongeni Ngcoya

Springs of Hope was founded in February 2003 by two young Christians that are living with HIV. Anne Ntombela (32) a widow and a mother of one, has lived with HIV for the past 13 years and Mbongeni Ngcoya (26), has lived with HIV for the past seven years.

About Anne

Anne, born in Kenya, met her late husband, a South African in exile in 1991. In 1992, four months after giving birth to her son, without counselling and proper support, she discovered she was HIV positive. Later, in1992, after receiving proper counselling, she disclosed to her family. Fortunately they were supportive. In 1994 she lost her husband to AIDS. This was a difficult time and there were no people who were open about their status in those days. In 1995, after struggling though depression, self-pity and fear in a foreign country, Anne started to disclose her status to more people. In 1996 she trained as an AIDS and HIV counsellor / educator. The same year she joined the University of Natal and started to study a Certificate in Adult Education. Presently Anne is pursuing her Masters degree in Adult Education at the University of KwaZulu Natal. In 2001 and 2002 Anne's health deteriorated and she developed AIDS and with a CD4 of 15 she almost gave up hope. But her family and friends never gave up; they encouraged and prayed for her. Her brother offered to buy her ARV drugs. Her health condition has improved since then and her greatest desire is to support and encourage others through sharing her testimony in local Churches in Pietermaritzburg. Anne is the Chairperson of the International Community of Women living with HIV and AIDS in South Africa (ICW-SA).

Anne Ntombela

About Mbongeni

Mbongeni, well known as "PG", works as a merchandiser at Spar and in his spare time runs a local talk show known as PG Talk. When he met Anne in 2001 she had just come out of hospital. In his search for new speakers for his show, he discovered Anne, the motivational speaker. He invited her to come and talk to the youth at his Church. After that they lost touch. Having led a normal youthful life, PG had had several unsafe sexual relationships before he became a Christian. After meeting with Anne, he started to be more aware of his health. Sadly, some of his past girlfriends passed away. In 2002, for a number of reasons, he decided to go for an HIV test. It was positive. After telling his brother, he called Anne and suggested that they start a support group. It took him a while to disclose to his parents - he feared how it would affect them, especially his mother who is sickly. Presently, PG enjoys full family support from his parents, brothers and sisters. He, too, has gone public about his status to the community of Pietermaritzburg.

About Springs of Hope

We had our first meeting to discuss the formation of a support group in November 2002. Working as a team we started to plan exactly what we wanted to achieve through running the support group. One of the greatest strengths and support we have experienced to help us cope is the Love of Christ through the Church, our families and friends. This has reminded us that the love of God is constant, and that through Christ everything is possible. Thus we have never given up on Hope.

Problem Statement

By the year 2001, KwaZulu-Natal province had the highest prevalence of HIV infections in South Africa. According to antenatal clinic statistics, 33.5% of the women-attending clinics tested HIV positive. Most of them were between the ages of 15 – 29 (MRC, 2002). Recent research by CAPRISA (February 2004) shows that these rates have increased to 40%.

Through working with people who are infected with HIV, we realise that most of them are despairing, they lose hope and stop dreaming into their future because of HIV. Young people - who are the future of our nation - are the most infected and affected. Parents live in fear of losing their children, and children live in fear of losing their parents.

Vision

Through the love of Christ, support and education, to create a community where people that are infected with HIV, or affected by HIV/AIDS, will be able to live comfortably without fear of discrimination.

Mission

In Christ there is hope, forgiveness, love and total freedom. Through the tender love of Christ, the seed of Hope we plant in others shall grow, from a small Spring of Hope, into a River of Hope. Hope that shall be passed on from one person to another, until our community is flooded with Hope and healed of the fear and stigma attached to HIV and AIDS.

Guiding Principles

To overcome despair

Through the Church, God has shown us a new life which we have embraced. We hope to be able to plant a seed of Hope in peoples' hearts, a hope that living with HIV is not as hopeless as it seems.

To support and encourage each other

Hope is vital for us if we have to win the fight against HIV and AIDS. This Hope has to be rekindled in different areas of our lives. Through supporting each other we wish to ensure that we maintain good health for all and empower each other in all areas of our lives.

To provide HIV and AIDS education

It is no secret that HIV has to find its way out of our bodies to infect someone else. We wish to reduce the rates of HIV infections through educating and encouraging one another to live positively.

To confront death with dignity

When death comes, we wish to be able to face it without fear and shame, to be able to die in dignity having realised our dreams and having lived our lives to the fullest.

Objectives

- to bring the love of Christ to the people infected and affected by HIV and AIDS by giving them spiritual and emotional support;
- to break the stigma surrounding HIV and AIDS;
- to reach as many people infected with HIV as possible in greater Pietermaritzburg;
- to help people infected with HIV, and hopefully their families, to accept their status;
- to provide HIV and AIDS education with a strong emphasis on positive living;
- to help people infected with HIV to look for possible solutions to their socio-economic problems;
- to encourage people to join existing support groups in their communities or establish branches of Springs of Hope support groups in their communities;
- to get Churches involved in the HIV/AIDS struggle;
- to network with other support groups and organizations involved in the fight against HIV and AIDS.

Our Target Group – Who we Work with and Help

We target HIV positive people that are not comfortable with disclosing their status with the hope of helping them adjust to their situation. As they accept their status, we hope to channel them to existing support groups in their communities or help them establish new branches of SOH support groups in their communities.

What We Have Achieved So Far

Support Group Meetings

Springs of Hope support Group Project had its first meeting at Tatham Art Gallery in February 2003. The number of members has grown from the 20s to the 80s, most of whom are women who are mothers. Our intention is to involve more men in our activities. We meet every third week and at least 20 to 25 people attend each meeting.

During the past year we have been able to support each other by sharing information during our meetings, referring members to CD (Communicable Disease) Clinics and welfare departments, and visiting one another at our homes and in hospitals. Sadly, we have lost six members to AIDS.

Advocacy

While volunteering, the support group members have been working effortlessly in supporting one another and people in their communities. We have also been involved in TAC (Treatment Action Campaign) marches and ICW-SA (International Committee of Women Living with HIV and AIDS – South Africa) forums to advocate on issues affecting people infected and affected by HIV and AIDS in South Africa.

Networking

Some of our members are members of The ICW -SA and one of our members is the Chairperson of the ICW- SA Executive Committee. Most of our members are members of TAC. We are part of the CINDI (Children In Distress Network) and Thandanani association is supporting us to educate children of some our members. We also have ensured that all our members get into Communicable Diseases Clinics.

Community Openness

In September 2003 we ran AIDS awareness in six schools in our communities. One of our main aims in doing this was to break the stigma while creating awareness by disclosing our HIV status and our roles in our communities.

Skills Development

Some members have received training in areas of work we are involved in so that they can be more effective in this work. This includes HIV and AIDS counselling, education, wellness programmes and home-based care.

Establishing Offices

While we continue to meet at Tatham Art Gallery, we now have offices at Tembaletu Community Centre. Tembaletu has offered us office space for six months free-of-charge while we seek funding. The office is where we run our administrative activities and counselling for members, their families and other community members.

Network Partners

We have realized that we cannot operate successfully if we try to go it alone. So we have established partnerships with the following NGO and Government structures:

- International Community of Women Living with HIV and AIDS – South Africa.
- Treatment Action Campaign
- CINDI (Children in Distress Network)
- Thandanani Association
- ISB
- Thembaletu Community Centre
- Communicable Diseases Clinics in Pietermaritzburg
- Provincial AIDS Unit
- Other support groups in Pietermaritzburg
- Tatham Art Gallery
- Centre for Adult Education – University of KwaZulu-Natal
- Local community resources (e.g.. Home-based care volunteers from different organizations and departments)

> We – the people infected with HIV, have the power to change the "face of HIV and break the stigma attached to HIV, but we need financial support to accomplish more.

Key Themes That Came Out of the Conference

The following were key themes that emerged during the papers and discussions at the conference. The recommended actions outlined came out of discussions at the conference as well as written recommendations submitted by participants for follow-up action/s after the conference.

Access to Health Care and other Support

- *How can we tell people about the benefits of testing, especially with the arrival of ARVs?*
- *How can we support people living with HIV to form neighbourhood support groups?*

POSSIBLE ACTION:

- Education programmes with a very practical and realistic focus.

Government Responsibility: Roll-out of ARVs

With regard to Government roll out of anti-retrovirals, there was concern that this too, was more accessible to those who have and who are in cities, but what about those who do not have and live far out in rural areas?

Other issues include:

- *How can we ensure that health workers do not take away the rights of women to Nevirapine?*
- *How can we lobby government to improve the basic care and respect offered to People living with HIV and AIDS in clinics and hospitals?*
- *Access to CD4 count checks: people are entitled to two CD4 counts a year. Can we lobby for this to get started as soon as possible?*

Government Responsibility: Improving the Quality of Public Health Care

In addition, while roll out of antiretrovirals is crucial, so too is improving the systems and services within health care facilities so that people are treated as if their lives actually do matter!

- *How do we keep Government accountable and ensure that it meets the needs of those who are most vulnerable?*

POSSIBLE ACTION:

We need to set up mechanisms to monitor health care provision and rollout of ARVs, if we can, by recording any stories of negative incidents, and submitting them to the Provincial AIDS Action Unit authorities, and receiving reportbacks of actions taken by them. Perhaps use the KZNCC Provincial Advocacy Office?

Power and Vulnerability: Poverty and Gender

Poverty increases the vulnerability of many people (especially women and girls), partly because they are more likely to resort to offering sexual 'favours' or turning to prostitution, and also because they are less likely to get out of destructive relationships because they fear losing their basic security. They are more vulnerable to HIV infection and becoming AIDS-sick.

Women and girls are usually expected to be the carers and so lose income, are forced to leave school, or even become infected (through ignorance mainly).

POSSIBLE ACTIONS:

Women (and men) need to be educated about the importance of disclosure, but support groups and HIV/AIDS counsellors need to stand by them as consequences can be severe if, for example, a partner or family chases one away.

In addition, women need to develop the skills to become more assertive and this involves working with men so that they understand their responsibility too.

- *How do we challenge power relations between men and women so that women (and men) are less vulnerable to HIV infection?*

Some Surprising Information – Vulnerability of Girls

Many young people refuse to accept any more HIV/AIDS awareness training as they are bored and it seems to have no impact. Why is it that most people know the basic facts, and yet still become infected?

The most at-risk group according to the Kaiser Foundation (2001) is girls between the ages of 15 and 19. If these girls are being tested at these ages, then it probably means that they are being infected three to five years earlier – which means at ages 12 – 16!

- *Are we doing enough for young people: are our messages and methodologies appropriate?*
- *What is making young girls so vulnerable, and how can we act to bring an end to this?*

POSSIBLE ACTION/S:

First and foremost, we need to evaluate our HIV/AIDS education programmes and methodologies, and check to what extent they are helping to reduce the vulnerability of women and girls.

Taking Care not to Marginalise Men

The issue of men came up often in the conference. On the one hand, we need to acknowledge the anger and frustration of women and allow the space for them to air this, but on the other we need to safeguard against alienating men. We need to get men more involved and think about what we can do as men and women. We need to start from a position that does not make men feel judged. Attitude and the language used to express issues of gender can antagonise men, and possibly make the situation worse

- *How do we ensure we do not just see men as a 'problem' and include men and women in a healing circle?"*
- *What can we do as men and women to create safe spaces where people can work through their pain and their need for positive, life-giving relationships?*
- *How do we involve men, but not at the expense of women?*

POSSIBLE ACTIONS:

- Men need to organise a conference where men speak out.
- We need to create an atmosphere in our gender and HIV/AIDS workshops where men and women can work together against the systemic problem of misuse of power and work towards alternative ways to relate.

Keeping HIV Negative People Negative

It is important not to ignore the need to keep encouraging people to stay negative - but the concern was raised that people are too afraid to know their status, which ends up fuelling new infections.

- *Young people often express boredom about 'more AIDS education', and yet behaviours are not changing.*
- *What new and creative ways can we use to help people face their status, and to motivate people to avoid behaviour that increases their risk of infection?*

POSSIBLE ACTIONS:

- We need to re-evaluate our education programmes, and see whether they really speak into the life experiences of the people, especially youth.
- We need to LISTEN to them to develop programmes that start from where they are at rather than speaking at them from above.

Poverty and Education

Women who are HIV positive and living in poverty experience added stigma via their children's schooling. Many children are turned away because their parents cannot afford school fees, yet our Government promises us free education for those who cannot pay.

- *Do principals of schools know that they shouldn't chase children or keep reports?*
- *Do parents who are indigent know that they can apply for exemption of fees?*
- *Are parents able to demand their rights when their children are discriminated against by exclusion or other punishments because of an inability to pay fees?*

ACTION:
As NGOs we should perhaps work together to publicise the regulations in local community newspapers or prepare information leaflets, or lobby the Department of Education to disseminate this information publicly and to principals as well? (We could offer to assist Government where appropriate?)

Access to Grants

Disability Grants: Too little too late

A major concern was Government's approach to giving out grants: why are they only giving grants at the end of life? This can cause an earlier death than necessary, as people cannot afford basic nutrition and the stress of extreme poverty can weaken the immune system. Also, a person can die before the money comes. Without a basic income grant (BIG) many people who are destitute have no hope of ever getting out of the poverty cycle, and many die prematurely because they cannot travel to health care facilities.

Early pensions for grannies caring for sick children and their grandchildren

Often elderly women have to stop working to take care of their AIDS-sick adult children and their grandchildren as well. But, unless they are 65, they are unable to access a pension and lose the disability grant when their child has died.

Government needs to consider a 'special pension' for under-age grannies unable to work due to domestic responsibilities as a result of HIV/AIDS.

POSSIBLE ACTION:

We need to lobby for earlier access to grants for People Living with HIV/AIDS (PLWHAs) and those caring for them, where necessary and appropriate?

Income Generation

Many people are trapped in a poverty cycle and are unable to escape this, even if they have skills or are highly motivated. This is worsened by HIV/AIDS but is a problem with or without HIV/AIDS.

- *How do we ensure the growth of small businesses so that they are not just about subsistence?*
- *How do we avoid duplication?*
- *The problem of “cashlessness”:- how can we think business in communities where there is no money?*

POSSIBLE ACTIONS:

- We need to take seriously people’s need for a livelihood, as much education is meaningless if people’s situation that caused their vulnerability in the first place does not change.
- We need to join the national and provincial lobby for a Basic Income Grant.

Government’s Responsibility for a Universal Basic Income Grant

All South Africans have a right to a basic income grant (BIG). There was a call to support those putting pressure on Government for BIG. This is a vital lifeline for the destitute to get out of the poverty cycle.

There were also repeated calls for civil society to get together as a force and lobby around HIV and keeping Government accountable.

POSSIBLE ACTIONS:
We need to join the national and provincial lobby for a Basic Income Grant, so that communities have start-up funds and/or buying power for any business or subsistence venture to work.

The Church

Who is the Church?

There was much debate about this question, and participants were cautioned not to apportion blame to clergy and other leadership: The Church is the people who make up the Church, and that means all of us!

We need to improve relationships between clergy and members. There is a need to share responsibility for HIV and to accept that HIV is destroying lives inside our churches as well as outside.

At present it is mainly women involved and we need to get more people involved and sharing the load, including men and youth

What is the role of the Church?

- Some people do not risk disclosing their status in church, for fear of being judged and isolated, which may be a form of self-stigmatisation (i.e.. believing that their status makes them unacceptable and thus isolating themselves in case it really happens).
- Although many people feel supported by their churches, this is mostly “as long as they don’t know my status” (one research participant in PACSA’s research).
- It is the silence about HIV/AIDS in our churches that sends the message to PLWHAs that they are not welcome, their experiences are shameful and there is no place for them.

How can we transform our Churches?

“*We need to have the* courage *to do Church differently”* – Bishop Purity Malinga (quoted in “The Church in an HIV+ World: A Handbook for churches” edited by Daniela Gennrich, 2004). The Church needs to undergo a change and this requires self evaluation.

We all need to take responsibility as members of the Church. Before we can change the church, we need to allow God to change us – admit our own fears and mistakes and search for a new vision.

We need to correct our pastors/priests where they are wrong , while admitting our own mistakes. We have rights and we must stand for them.

- *Do we take enough trouble to take care of people?*
- *Are we prepared to risk speaking out about HIV/AIDS, so that people feel safe to talk about their problems?*
- *What does Christ require of us as Christians in our HIV positive world?*

POSSIBLE ACTION/S:

- To start with - we need to get our mindset right, and take responsibility for being part of the church rather than blaming others in the church – as a starting point to looking at what our role might be in the pandemic.
- We need to examine ourselves and ask God to transform us first.
- We need to speak about HIV/AIDS, even if we are opposed.
- Many of us work in NGOs that tackle HIV/AIDS, but we do nothing to mobilise our churches – let’s do it!

Stigma, Loneliness and Disclosure

The issue of stigma was discussed many times. The PACSA study suggested that where people had access to medication they were no longer afraid to come out about their HIV status. It also pointed to the role of poverty in preventing people from admitting their HIV positive status because they fear losing the little bit of security they have by being rejected by those on whom they depend for their basic needs. Whether or not these are linked, the message was clear: we have to deal with, and challenge, the stigma attached to HIV.

- *How do we find meaningful and effective ways to do away with the stigma attached to HIV/AIDS?*
- *Do we need to deal with our own prejudices and fears first?*

POSSIBLE ACTIONS:

- Face the demon of HIV/AIDS in our own lives first!
- Find others of like mind and work together.
- Recognise the link between economic dependence and the inability to disclose or cope with stigma, and find ways to help people become more economically independent.

Collaboration

Participants felt there was a need for collaboration on a number of levels:

Churches and NGOs

HIV/AIDS involves many different aspects of life, and no single organisation can cover all of these. For example, there was a lot of concern about the difficulty the Church has in accessing funding to provide services. It was suggested that there would be a lot of benefit from collaborations with organisations such as NGOs - who fit the criteria of funders - with the Church becoming the silent partner in the collaboration.

Churches forming partnerships with each other

Some Churches are financially rich and perhaps there should be a system where we can link the richer with the poorer (financially). However, the conference acknowledged that there are different kinds of poverty and richness, so financially poorer churches can also share their riches with those who are financially better off.

Churches forming partnerships with Government Departments

The Government has repeatedly expressed the desire to work with churches to improve service delivery, particularly with respect to poverty relief. But we should also take the initiative, where we think government needs to take more action, such as improving health care in local hospitals, etc.

POSSIBLE ACTION:

- PACSA to follow up with the Department of Social Welfare a statement by Minister Zola Skweyiya that there is lots of money available - for emergency food distribution and HIV/AIDS work - that has not been spent due to lack of infrastructure, especially in rural areas, and that they would like to work with the Church?
- Explore use of KZNCC Advocacy Office to establish an HIV/AIDS Monitoring network, to assist Government to root out problems and improve their services, as outlined in the National Integrated Plan.

Involvement of People Living with HIV/AIDS

A strong theme was the need to involve PWAs, and if necessary empower them to take the lead in our structures. We cannot understand HIV unless we have lived it so any work we do must start with PWAs and end with PWAs.

POSSIBLE ACTION/S:

- Those of us who are negative or do not know our status, should have the humility to take the lead from PLWHAs.
- Those of us who are HIV+ should try to take up that leading role, where they feel supported to do so.

Research Ethics

There was a concern about the intention of research and how it is used, particularly when the research involves people whose lives are at risk because of their poverty, and/or their HIV status. People who need it the most should benefit from research: it should not just be there for the recognition of the researcher, or for the advancement of academic knowledge.

- *How do we ensure that HIV /AIDS research done is ethical, humane and in the interests of the subjects of research?*

POSSIBLE ACTION: Raise this issue in academic forums, where appropriate.

Immediate Practical Suggestions from the Conference

- If possible, PACSA should try to partner with different CBO's and NGO's, especially in Mpophomeni, to speak in one voice to increase their capacity.
- PACSA should call a meeting of Churches around Pietermaritzburg to update them of Conference concerns and hear their response.
- During the presentations, some people indicated that they would like to get more support in agricultural issues. The Farmers Support Group could take this issue forward in a MIDNET meeting to see what agricultural organisations in the region can offer.
- PACSA should take up with the Department of Education the concern that the prevalence of AIDS in the age of under sixteen years has increased dramatically, as this raises the question of how much AIDS education is done at schools.
- HIVAN has offered to place the reports, papers, and key decisions/ findings/ suggestions of this workshop on the HIVAN Website FBO (Faith Based Organisation) section. This will allow for everyone to refer to these documents and for influential people to see them. It's a way of archiving important decisions of discussions so that they can be accessed again when and as needed, rather than gathering dust.
- PACSA should prepare a pamphlet that summarises key issues for people living with HIV/AIDS.

Some Feedback on the Conference

A Letter from Friends

Dear PACSA

Thank you all very much for such a well organised conference and book launch. We were able to meet and hear about other practical projects which had encouraged people at St Josephs to think about different ways of approaching HIV/AIDS. Our first follow up from the conference will be to organise a social day and ask PWAs to join us.

Our team was so impressed with the banners and wall hanging, plus the big candle and tea candles and flowers. We want to take your ideas back to the mission and surrounding areas.

The conference was an excellent opportunity for us to make friends (often working in the sticks in the North is quite isolating) so this opportunity was very important.

We came away with posters, booklets, new friends and inspired – so thank you. We will share the resources with four adjacent parishes and their outstations and with the Anglican Archdeaconry.

Lastly, we appreciate the times set aside to pray, reflect and be still with our creator central to all things – "In God we live, and move, and have our being." This is almost difficult to include in time pressed conferences. Your creativity made this a reality. Thank you.

May God hold all of you in the palm of his/her hand.

Mama Regina Nwenya, Fisani Mkhize and Jean Davidson

> "Thank you PACSA for a very well organized, stimulating and interesting conference. We came from rural KZN and met new friends, exchanged ideas and learnt a lot. SIYABONGA"