A COMMUNITY MAKING CHANGE

HIV/AIDS PREVENTION GROUP BELA-BELA

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about this publication

This publication is the combined outcome of two separate HAPG-focused bodies of work carried out for Oxfam individually by Scott Drimie and Gladys Ryan. The work took place in 2013 and 2014 respectively. Oxfam has combined the work of each of these contributors to provide a sense of the richness and depth of HAPG’s story.

The HIV/AIDS Prevention Group (HAPG) recognises that as knowledge about HIV and AIDS has evolved the naming convention that was originally ‘HIV/AIDS’ has generally changed to ‘HIV and AIDS’. The organisation was established many years prior to these advances and the subsequent change in naming convention and as such ‘HIV/AIDS’ has been retained in its original format in the organisation’s formal name.
Bela-Bela is a place that is hard to define. The small rural town has steadily changed over the past two decades yet still exudes the shape and form of a difficult past. The topography also eludes definition. The flat, dusty veld seems to run unbroken towards a distant horizon marked by mountains, yet the abundant acacia trees hide a broken country, limiting the view to a few metres. Much remains hidden.

Driving northwards, about 100 km from Pretoria, on the N1 towards Polokwane and distant Zimbabwe, a mountain range, the Waterberg, juts out to the west, forming a grey-blue barrier that shimmers in the intense summer heat. Turning towards these mountains, Bela-Bela stands as a gateway to the mineral-rich hinterland.

Wildlife-proof fences line the sides of the road, an indication that many of the former livestock and maize farms now run herds of wild game instead, catering for tourists who come to view them. As the road draws nearer to its destination, new settlements become visible. These sprawl out around the old agricultural centre and town. The nature of the local economy becomes more evident as numerous farm stalls appear, selling seasonal produce transported from distant commercial farms. Hawkers sell hardwood sourced from the bush, hinting at another economy.

The massive grain silos shadow the older township. From the early 1990s transformation of the agrarian system began to result in land use changes. Wildlife management and tourism became safer options for commercial farmers in the face of the threats that the labour-intensive systems of the past were perceived to invite from newly introduced land tenure policies. Large numbers of farm workers subsequently left the countryside, many homeless due to evictions or farms closing as farmers sold, changed focus or downscaled.

Compounding this migration, many other rural inhabitants have left the communal areas in search of work to help sustain a fragile livelihood system. The population of Bela-Bela has thus swelled, growing from around 10,000 people in 1982 to over 65,000 people 30 years later. The town welcomes visitors to the hot springs, the waterfront, and numerous bed and breakfast establishments, all serviced by restaurants and shopping centres. This perception of a vibrant economy distracts from another reality, where the majority of adults are either unemployed or underemployed. Generally, households attempt to procure income through providing cheap, unskilled labour; engaging in precarious self-employment; or applying for government grants.

Bela-Bela, a rural town of predictable disparity, and a reflection of South Africa’s unjust history, is the setting for the HIV/AIDS Prevention Group (HAPG). When the organisation was started in 1996, HIV had taken root and AIDS was resulting in high levels of mortality. In a context where treatment was unknown, stigma, fear, political apathy and traditional beliefs allowed the epidemic to continue its spread. HAPG stepped into this “perfect storm” both with the community and as a part of it, to embark upon a journey, the story of which reflects the severe impact of the AIDS epidemic in South Africa. The triumphs of HAPG in the face of such daunting odds are reason enough for its story to be told, pivoting on the individuals that have made it a success.
**WHY HAPG IS IMPORTANT**

HAPG is the embodiment of the possibility of providing appropriate HIV and AIDS services in difficult conditions, of proving that even in a context of poverty and social exclusion, residents can access a well-administered medical care and antiretroviral programme. HAPG has demonstrated that a successful health programme can be staffed and run by a cohort of mainly laypeople who can condense and administer complex health procedures. It has shown that if you provide treatment that works, people will use it.

HAPG has revealed that the “art of the possible” is very powerful and that through collective agency a functioning and effective health care system can be created.

HAPG has led the way in Limpopo in pioneering layperson-managed clinics supervised by an HIV and AIDS specialist administering antiretroviral treatment (ART) as a matter of course, in a province that is still struggling to provide an effective primary health care system. A network of people has come to see that, through the power of their own deeds, they can turn around a situation of death, despair, fear and shame, making it one where people can come forward and claim the right to stay alive.

**RAKGADI – MY FATHER’S SISTER – THE ONE WHO LOOKS AFTER THE CHILDREN**

Cecile Manhaeve’s life in what was then known as Warmbaths (now Bela-Bela) began in the early 1980s, and was an extreme contrast to her youth in Belgium. The white, mostly Afrikaans-speaking population of the town regarded her with suspicion, many looking at her as an outsider who was “overly-friendly” with black people. This was at the height of the struggle against apartheid, with the area a hotspot of political dissent. Using the church as her base, Cecile developed strong networks and friendships in the black community. Her two worlds stood in direct juxtaposition.

That Cecile settled in Bela-Bela was purely coincidental, that she lives in Africa is a matter of choice. She arrived in South Africa in 1982, committed to working in “development”, using old family and church connections to guide her. She had been born near Kinshasa in the Belgian Congo (now the Democratic Republic of Congo) but, as both Cecile and her father had contracted malaria, the family moved to Belgium during her childhood. Although they had wanted to return to the Congo, liver damage caused by the disease ruled out work in areas endemic with the Anopheles mosquito. Cecile always had a deep yearning to return to the continent where she was born, to “fill in what I had in my imagination about Africa”, she says. Cecile’s aunt had fled the war in the Congo in the early 1960s and settled in Rooiwal near Pretoria. Another aunt had taken up a teaching position on the outskirts of Pietersburg (now Polokwane) in 1959. The connections with Cecile’s family in South Africa were strong and she was drawn to the country to visit them. After her visit, a chance conversation with a priest on her flight back to Belgium laid the seeds of her return to Africa when he told her about a group of Belgian volunteers working with him on a two-year contract in Warmbaths. And thus,
in 1982 she left the multi-national company where she had been working as an accountant and returned to Warmbaths to join the church group to run leadership courses in the diocese and township beyond her own church congregation. The early 1980s was a challenging period to work in South Africa in the development sector as a foreigner. The apartheid government was intensely mistrustful of an outsider’s interaction with black people. Unsurprisingly, training initiatives held in the townships came under intense scrutiny. Cecile soon found herself being tailed by the security branch (a section of the South African police, also called the “special branch”). The township of Warmbaths was known for supporting the African National Congress (ANC), with a number of activists emerging from the area – a strong police presence, an active “divide and rule” strategy using ethnic or language divisions in schools, and ongoing surveillance were the government’s response. (A visit from Belgian officials twenty years later revealed Cecile’s security branch file and confirmed the nature of the investigation that Cecile had found herself under.) In 1989 the harassment by the police ultimately led to the cessation of the leadership courses that Cecile was running. It did, however, also lead to community members asking Cecile to work with them, which led to her considering herself a community member.

 Cecile was involved in starting the Bela-Bela Welfare Society, which arose as an initiative to bring the piecemeal strands of welfare work together in the township. In the 1980s, the main focus of the society was on widespread child abuse. The society’s objective was to support children by reporting cases and working with magistrates and court officials to act on the reports. Through organising community meetings and supporting small groups in neighbourhoods, the welfare society identified what was needed to improve the community. The approach of the welfare society was to consult with the community at every stage and to agree what was to be done about issues.

Cecile recalls: “When I first went home [to Belgium] after two years, they asked, ‘So what have you been busy with?’ I said, ‘Nothing, just sitting and listening.’ And they asked, ‘Don’t you need money?’ and I said ‘No’. It was only when the community came to me after six years and said they were ready to do things, I eventually came back with money.”

It was then that Cecile was involved in helping set up preschools and a school for mentally disabled children; such people were usually hidden by families and denied the special care that they required. Cecile was also instrumental in starting a day-care centre in 1990 where for a small fee children were supported in a safe environment. It was through this that the Bela-Bela Welfare Society identified what was needed to improve the community. The approach of the welfare society was to consult with the community at every stage and to agree what was to be done about issues.

A FOUNDING FATHER – MARCUS MOROKE

Marcus Moroke, the chairperson of the Bela-Bela Welfare Society through the 1980s and 1990s, is one of the founder members of HAPG. He came to Warmbaths as a young man in 1978, when he was promoted to the position of principal of Mmanamwa Memorial Primary School. In the 1970s and 1980s, tuberculosis (TB) was the major cause of death in Warmbaths and, with the support of the municipality, he immediately decided to start a care group for people with TB. He recruited other like-minded volunteers to join him and formed a committee with the first task being to gather people with TB together and give them support in dealing with the disease. The committee encouraged the people to go the local clinic to collect their weekly tablets, and those who didn’t arrive for their medication were visited at their homes by staff from the municipality. The people with TB were encouraged to plant vegetable gardens and supplied with supplementary food parcels, donated by the local supermarkets and agricultural co-operatives. In the first year, after six months, virtually the entire group was free of TB. The committee replicated its efforts, gathering together another group. At the end of the year they organised a “grand celebration” using donations from the community to have a party.
Mr Moroke believes that the key to the success of this experience was the locally representative committee that reinforced its connections with the community through volunteers, as well as with local authorities.

He says another important lesson was the focus on good nutrition to complement the medication being used to treat the TB infections.

The Bela-Bela Welfare Society, run by the Ministers’ Fraternal (a group that brought together the religious ministers from different churches), emerged out of this TB initiative and started a number of projects over the years, one of them being the HIV programme. It was out of this grouping that HAPG emerged, with Cecile raising funds from Belgium to assist. The welfare society initiated a number of projects in Bela-Bela, including two creches. The society also established a school for mentally disabled children; it received local donations and relied on unqualified teachers who “did a splendid job”, according to Mr Moroke. Eventually the society applied to the Department of Education to formally establish a school for the children. The Department of Education gave permission to erect the school, donating money towards building the structure. After the 1994 elections, the new government donated a substantial amount to the institution, allowing for a boarding school to be built. The school now runs efficiently on its own with support from the Department of Education.

Mr Moroke has since retired from teaching and was recently ordained a bishop. He continues to work closely with HAPG and is involved in community work through the Ministers’ Fraternal.

THE BEGINNING OF THE HIV/AIDS PREVENTION GROUP

In telling the story of HIV in Bela-Bela, Mr Moroke reflects on how the experiences gained in combating TB were so relevant for addressing HIV and AIDS. He argues that the epidemic was certainly present in the 1980s but that it was not widely recognised until the mid-1990s, through the increasing number of chronically ill people in the community. Sister Winifred Moloisane relates a similar story. She first met Cecile in the 1980s through Cecile’s activism within the community. It was only in the late 1980s that she came to work with Cecile on health issues that were becoming prominent. At this time the township was not developed and was not able to cater for the increases in people migrating from the farms and from Zimbabwe in search of work. A severe drought in 1992 contributed to the failure of a number of farms in the district and this further exacerbated the influx to the township of people previously employed on the farms. Bela-Bela was small, with already high unemployment levels, and the newly arrived farm workers had few skills for an urban existence. Sister Winifred reflects “It was also at this time that the monster called HIV started to reveal itself. People were in denial about its existence and many believed that AIDS stood for ‘American Idea of Discouraging Sex’.” Thus in 1992 the Bela-Bela Welfare Society recognised that it needed a clear strategy to address HIV and AIDS. Cecile was asked to learn as much as possible and to bring that knowledge back. In this way, HAPG eventually emerged, organically, through a community-led response to a common challenge. Taking its cue from the
community mandate, HAPG slowly took shape, continually in dialogue, never developing anything the community did not ask for. When it was realised what it was that they were facing, the immediate course of action was to extend what Cecile had learned to the community. It was difficult for people to understand what the epidemic was about. The virus was seen as a persona that was brought into the community; a deadly presence that could not be spoken about. The most challenging question was why it could not be cured like TB. The lack of an answer to this question seriously undermined the confidence of the community leadership. They had been part of the groundswell that eventually saw the demise of apartheid and the retreat of the security police from their township. TB had been contained to some extent. People were looking to a dramatically improved life under the new democratically-elected government, yet here was something that threatened to overwhelm these successes.

A board of directors was appointed to steer the group, which was supported by a management committee to supervise day-to-day operations. With Cecile’s leadership on the ground, it was agreed that the first priority was a large-scale awareness programme to build knowledge about HIV and AIDS. Cecile had immersed herself in courses offered by the AIDS Training, Information and Counselling Centre (ATICC), in Johannesburg between 1992 and 1996, building her expertise in awareness and counselling. She believed that without community solidarity, very little would be achieved. A central tenet of the awareness campaign was how to prevent the virus from entering the body. This was a difficult concept for many people, and the difficulty of spreading this information was exacerbated by the challenges of doing so in a context of denial and stigma. Yet by May 1996, HAPG volunteers were conducting weekly awareness campaigns around the township. The work gradually expanded to include counselling and training of counsellors, establishing support groups for people living with HIV (PLHIV), home-based care services, care for orphaned children and provision of treatment. Recently, when asked to look back over the past decade and a half, many of the first board members of HAPG, the “old guard”, were almost incredulous at how things had changed.

Mr Moroke agreed that at the beginning people did not understand HIV and that the primary role of HAPG was to build knowledge.

A key strategy that was employed was to work with people who were infected and through them seek community acceptance and understanding.

It was only after this that HAPG gained real traction in Bela-Bela. Doing so was immensely difficult; widespread stigma existed so people avoided individuals who had disclosed that they were HIV positive, or were assumed to be HIV positive – and were silent about those HIV-positive people who were living with them in their homes. The first group of volunteers, “the first support group”, all of whom were living with HIV, led the awareness campaign. When encouraged to think back to this time and tell their stories these volunteers outlined the extraordinary challenges that being associated with the virus carried, including immediate isolation and rejection. Many of the volunteers did not want it known that they were HIV positive, as they recognised that the community was not ready to accept them; they agreed that “it was as if we had leprosy”. Mr Moroke believes that through persistence in working with and supporting people living with HIV, HAPG began to plan and drive a mass awareness campaign that combated stigma and ultimately resulted in a shift in community attitudes.
HAPG was like a pebble dropping into the pond of Bela-Bela. Slowly but surely the numbers of people who understood the epidemic began to grow from individuals to families to the larger networks of kin. This built the strength of the community to engage with stigma and denial directly. By building on existing networks, especially those pivoting on churches, schools and clinics, HAPG began to have an impact.

In a context where stigma was widespread, the first step was to build the confidence of the volunteers who then drove the awareness campaign. Confidence was nurtured in the small support groups which provided a space for sharing and listening. One challenge was the need to secure a place where meetings could be held while still ensuring the privacy of those volunteers who were afraid of being identified as being HIV positive. As the awareness campaign unfolded, increasing numbers of people were encouraged to come to the clinic for support. At this stage, HAPG centred on a small office with no facility for meetings in the clinic premises. Despite this lack of space, counselling was made available and people were encouraged to talk openly about their status. The number of groups slowly began to increase.

The first group that began to take shape consisted of volunteers working together with nurses from the nearby clinic, with the provision of mutual support holding the group together. In time this group engaged the community through schools and churches. The message was clear: HIV was here to stay even if it was unwanted. Fizo Lelaka, who was one of the original nurses and is now the operational manager of the Wellness Clinic at Bela-Bela Hospital (officially Warmbad/Warmbaths Hospital), believes that the schools were the most important strategic entry point to facilitate a change in attitude. Children were often curious, wanting to touch those who had spoken out about their infection.

This began to change perceptions, which in turn built the confidence of the group. By creating acceptance amongst the youth, a new generation of leaders within the community were created. A growing number of HIV-positive people became counsellors and led the prevention strategy through talking at schools in Bela-Bela and more broadly across the district. Complementing this, church ministers from various denominations encouraged acceptance of people with HIV particularly within families.

The epidemic has a much greater impact on people who have a low income, particularly if they cannot access nutritious foods, and services such as clean water. Their physiological condition is often compromised by inadequate living conditions, lack of access to basic health services and poor nutrition. As the virus has a more profound impact on an already compromised immune system, increasing the food and nutrition security of people became an imperative for HAPG. Focusing on this issue in 1996, the first group asked for a small portion of land from one of the churches on which to grow vegetables for inclusion in "food parcels". At this stage there was no access to government disability grants or broader welfare support for community members, let alone the drugs needed to combat HIV and AIDS. The combination of a safe space to talk openly and build mutual support, as well as occasional food parcels, along with increasing community awareness and openness, laid a firm foundation for a sustained impact. From these small beginnings, the community started to accommodate the initiative, which led to Bela-Bela slowly becoming a more tolerant place. In time, HAPG began to conduct far more than awareness campaigns. Its work...
grew to include home-based care, support for orphaned and vulnerable children, support groups for people living with HIV and AIDS, HIV testing and treatment adherence, and eventually counselling and mentoring when antiretroviral therapy (ART) became available. A very difficult period, however, lay ahead, before all these new activities became a reality.

THE FIRST SUPPORT GROUP

Support groups and home-based care services were the only available interventions to address HIV and AIDS in Bela-Bela in the late 1990s. Treatment was unavailable from the government facilities and usually too expensive to secure privately. The support groups were made up of ten or so people, guided by a counsellor who was specifically trained by Cecile, and they provided fellowship and support to people infected with HIV. Complementing this, a group of volunteer nurses were mobilised to go into the community to provide basic support, both in terms of social and health care. The counsellors often accompanied them and ultimately took over this function. In many ways this was an early version of what became the government home-based care programme of today.

An important and poignant dimension of the HAPS home-based care initiative was the introduction of “memory boxes” – a process that enabled sick parents to secure memories of themselves and their families for their children. Along with the considerable psychological comfort this process afforded the parents, it also provided clarity about who the parents felt should care for their children after their deaths. Since again this initiative and its effects did a great deal to change attitudes to HIV and build solidarity amongst the community.

The first generation of counsellors and nurses provide important insights into this difficult time, both in terms of the challenges faced by the community and their own struggles. The nurses who helped establish the first support group, Fizo Lelaka, Badya Malele, Petronella Ramolotja and Rebecca Baloyi, explained that their approach was to counsel people about HIV both before and after testing, and, if necessary, to coach them about disclosing to their family. It was Cecile, using the knowledge she had gathered, who initially trained the nurses in these counselling skills and how to provide care for PLHIV. The importance of being able to sustain the immune systems of people before and after testing and diagnosis was a key issue. As people often did not want to be tested, and as the symptoms of TB and diabetes were frequently very similar to those of people infected with HIV, Cecile and the team had to consider whether people they were seeing might instead have TB or diabetes rather than be HIV positive. They had to develop how to provide care for PLHIV.

Fizo’s anecdote is a fitting introduction to the nurses who started the first support group at HAPS. They were really like rays of sunshine in a very bleak time in the history of South Africa. HIV came in, silent and stealthy, taking people by surprise with its far-reaching effects on so many, particularly the poor. Fizo and the other nurses understood the stigma associated with HIV and accommodated their patients in many ways, showing caring, consideration and a great degree of patience.

Fizo started working with HAPS in 1995. After having studied midwifery, she had requested to be based at the hospital’s wellness clinic in Bela-Bela (this was surprising to her superiors, because she could have earned more money at the hospital). It was her volunteer work at HAPS that inspired the passion in her to work with people living with HIV, and it is her dedication to people’s wellbeing that has kept her supporting this work in her spare time.

Fizo recalls a time when the Department of Health, through her manager, tried to get her to stop helping at the HAPS clinic. She recounts: “The Department of Health said, ‘you must stop helping Cecile’ and it was a very hard thing … and then I said, ‘Rather than stopping to help Cecile I’d rather resign now from the hospital; rather I will give you 24-hours’ notice and leave. Because if I leave now, and resign, you will get somebody to fill my place, but at Cecile’s I don’t think there will be anybody to fill my place. And please tell them at the province that even if they can fly with the aeroplane up there, they will see me at Cecile’s place. They will see me there!’ She laughs and continues with her story: “I’m going to go helping the community of Bela-Bela. I won’t stop.”

Petronella had similar experiences – with her superiors trying to get her to stop doing voluntary work at HAPS.
Petronella is originally from the Free State province and came to train at a private hospital in Bela-Bela, then married and settled in Bela-Bela. Petronella already knew Cecile because they attended the same church and one day Fizo, who was also a parishioner at the church, approached her and told her what they were doing and invited her to volunteer. At the time Petronella was Operations Manager of the Intensive Care Unit; now she is the manager of the MDR-TB hospital in Modimolle.

As a volunteer at HAPG, Petronella joined Rebecca and Fizo doing home-based care. "We were ... counselling the patients, doing home visits, like after the patient has been diagnosed just to make sure that the patient is staying in a conducive environment. We also did a counselling course with University of South Africa (UNISA)."

She recalls, too, how reluctant some people were to disclose. "They thought HIV was a death sentence and then, you know, it was very difficult because sometimes you had to visit somebody, maybe a family, and then the husband doesn’t know ... But we really had a passion; we couldn’t just leave ... The government felt exposed ... they felt threatened as they were not offering ARVs [antiretroviral drugs]." she says.

Rebecca began as a volunteer in 1996, after World AIDS Day in December, only leaving in 2007 when she went to work in the North West province. On returning to Bela-Bela in 2011, she immediately rejoined the team at HAPG. Her current work involves tracing people with TB who have defaulted on their treatment.

Gladys began to volunteer with the other nurses at HAPG in 1997 when they were involved in HIV awareness raising and health education. She tells, "At first it was difficult because some of the people didn’t even want to be tested. The minute you talked about HIV the person would tell you ‘hm hm (no no), I don’t want (to be tested) because the people will talk about me.’"

Some community members were even ashamed to have Cecile’s car parked outside their homes, for fear that its presence would be associated with HIV and AIDS. The nurses and others at HAPG persevered and, as time went on, more and more people came for assistance. The nurses remember with fondness the awareness campaigns they did, visiting schools, churches and other places where people gathered. They would visit people at their homes, constantly encouraging them to visit the clinic. In time, community members got to trust these nurses above all others. It is this dedication to their community and commitment to their calling that led these four nurses to offer their support to HAPG in the early days of the epidemic.

According to Rebecca, people preferred coming to HAPG because “When I was with them I would listen to them. I would explain whatever problems they had; but with other people – some of the nurses – they still had that stigma or were afraid to touch or nurse or even to talk about HIV.

The [hospital-based] nurses were seeing very sick people with bed sores – the signs and symptoms were very obvious – but they didn’t know, or didn’t know how to deal with them. We [the HAPG nurses] could see this person might have HIV [or AIDS] and then do counselling and testing with them.”
At that time, people would not always go to the clinic, ending up so sick they would be bedridden. The HAPG nurses, doing their home-based care, would have to do everything, from giving bed baths to dressing bed sores. It was their patience and the testimonies of the support group members that slowly gained people’s trust and got them to go to the clinic despite their fears of a positive HIV test result. For those who had no money to go to the clinic or the hospital, HAPG offered transport, food parcels and payment of fees where necessary.

Petronella recalls what she observed: “You know... during that time, there was a discrimination of patients that were suffering. For example if they were going to the hospital... and casualty [the emergency ward] was just divided with curtains and then somebody would be talking to the person loudly and talking about HIV and scolding them. I even recall a doctor saying, ‘You are going to die, you won’t make it.’ Cecile – I don’t know how to say it – was the one who saved all these patients by starting with the ARVs.”

Gladys recalls how pregnant women who tested HIV positive were told they should be sterilised immediately because it was not known then that the baby could be born HIV negative. “So there are some of the mothers who are still living now, they are there now, they are living with HIV and some of them still come to me and ask if they can still have another child...”

The nurses would go on home visits before they began their shifts at their respective places of work, and would be back after they finished their normal day’s work. When they diagnosed people at the hospital they would send them on to the HAPG clinic for treatment. There were also many losses along the way; times that caused the nurses tremendous sadness, as Rebecca shares: “When you come back from the patient you would feel down... some of them you would see them... and you would know that this one is going and at the end you would see this patient dead.”

They were given hope by the patients whose lives were saved. All four nurses shared stories of patients who would have been dead, but for their care. Fizo shares a story of a young woman who was close to death. Her sister was a nurse and had no hope for her. Fizo persevered with her care for this woman, sitting with her and trying to convince her sister to allow ARVs. This woman is alive today and Fizo and Cecile call her the “Miracle of God”. Fizo tells how this woman subsequently brought her own daughter to HAPG. “...once, she brought her daughter to wellness [HAPG] and said ‘I brought her here; where you are, Fizo; where you are, I know she’s going to survive... Don’t tell me to go to the location [back home]. I came here to you’.”

Rebecca shares a story of a person who couldn’t walk, who was holding onto the walls to keep herself upright; her little brothers would feed her when they came home from school. Rebecca told her that being HIV positive did not mean she would die, and that she needed to take care of herself. Two weeks later Rebecca didn’t recognise her when she came in the HAPG clinic. Rebecca says: “To tell you today, she’s having a baby. She’s a counsellor at the hospital. If she didn’t come or I didn’t do something, she would have been dead today. It was like she had lost hope.” Petronella and Gladys relate similar experiences. Seeing the survivors kept them going. They felt that people surviving meant they were doing something right – it was like a thank you to them.
Fizo, Gladys, Petronella and Rebecca are still with HAPG today, still working as volunteers after hours. When they were asked what is it that is special about the HAPG clinic and those who work there, their responses included the following: The passion we have for the patients; the medication – making ARVs available; the staff – some of them are themselves clients and they have an understanding of what their patients are going through and the passion and dedication to offer them meaningful support; the experience of the people in the organisation, including Cecile and Dr Norbert Mjdeka who play a pivotal role; and, above all, the respect.

THE FIRST SUPPORT GROUP – PIONEERING CHANGE

"Here are your results. You are having AIDS and you are going to die." This is how Sophy Maoka recalls first hearing the news that she was HIV positive.

She describes her reaction to hearing those words: "I was so scared; I only heard about it from the radio, that it’s killing people. I cried and cried. I said to them, ‘call my parents’ and when they arrived I didn’t stop crying. When I saw them I cried worse and then I told them I’m dying and I have AIDS. I could feel I was dying the way they disclosed it to me; I was so scared I didn’t know when it is going to happen."

Today Sophy is an example of the power of the human spirit and a testament to HAPG’s incredible work.

Sophy, Caroline Mabusela, Elias Mabuza and Eva Monama were members of the first HAPG support group; today they play an invaluable role at HAPG as counsellors and trainers.

When Caroline joined the support group she didn’t believe the other members were also HIV positive. She was convinced that she was the only person living with HIV and after the meeting, when Cecile asked her how she felt, she replied "To me it seems like you just brought people to convince me that they are sick, but they are not."

Sophy experienced similar feelings of scepticism, believing the others were lying to her about their being HIV positive. It was only when she saw Eva, who was just as small in stature as her, that she began to believe this might be a place of support and that they might actually all be in a similar situation. As they continued talking and sharing they began to trust each other, and then to need one another and rely on the camaraderie and friendship that developed through the support group.

At the time of the first support group at HAPG, in 1999, HIV was often perceived as an unfamiliar, mysterious and "terrifying enemy". Perhaps because of this, as well as society’s judgmental views around sex and sexuality, there was a strong negative reaction towards people even suspected of being HIV positive. Those people were treated like pariahs and ostracised. Caroline, Sophy, Elias and Eva recalled only too well the attacks levelled at them. Elias recalls "When we went out to disclose our status, some people didn’t want to touch us or greet us; when we went to Ellisras (now Lephalale, a town about 204 km from Bela-Bela) some of us were looking healthy, I was not looking healthy. They said, ‘it seems they are not HIV positive but that old man, we think he’s the one who has…’"

Elias had similar experiences at schools, where the young people would tell him he would never live beyond 2004. People would look at them, fascinated at how a person with HIV eats. He says, “We were [treated] like animals. They wanted to see how we were doing things because we were HIV positive. And when we ate food they were sitting in front of us looking how a person with HIV eats.”

Support group members found that their assistance was no longer welcome at community functions such as funerals and that people would create space between them when travelling in minibus taxis. Elias, perhaps, felt it most. He thought he had brought a disease from Zimbabwe and felt ashamed. He projected his own feelings onto people in the community. While there was indeed a strong stigma attached to people with HIV and while community members did talk about them, sometimes he would assume they were doing that without having any proof of it being the case. He explains, “It was hard going into [the] location [community] and being pointed at. You see people talking about their own things, and you think they are talking about you … it was hard to go round.” And yet, as Sophy pointed out, the community members themselves didn’t know their own statuses.

Eva found out through a boyfriend’s death that she was HIV positive. When he died, community members spoke about it and she was anxious. Her pastor suggested she go to the clinic for an HIV test. At that time she had to wait three days for her test results. She explains, "It was difficult to accept because I was not sick. I was not feeling pain. I was like Eva I know, but the HIV was running inside my body.”

At that time there were no ARVs, and people felt that having HIV was a death sentence, that the end result would only be premature death. Sladys invited Eva to join the support group – a space that was to become for Eva and her peers their anchor and a source of hope. For her, the support group was the only ‘medicine’ in the time before the ARVs.

With the vegetable garden, and the daily gatherings to talk and share, they began to have hope. It was not long before they started doing HIV awareness raising voluntarily and receiving food parcels. Cecile fundraised for them to receive stipends. Little by little, the small team became more confident and generated hope for a long and happy life.

Slowly the members became brave enough to disclose their HIV positive status. Never pushed, but constantly supported by HAPG, as HIV and AIDS became demystified, as they came to understand what it was, and what part they could play in keeping themselves well, they became more confident. The support they received from one another bolstered their confidence and slowly they began to disclose their HIV positive status to the community. The support group gave them the courage to tell people the truth.

For members, the support group became more than a space to get together to talk about HIV. They got to develop a deep love and camaraderie for one another.

They gave each other courage and strength to do things, saying, “if that one can do it, so can I.”
The support group is central to the HAPG story. The support group members’ journeys — learning to face stigma, to challenge the status quo, to walk with their heads held high and disconnect from the criticism and disrespect shown to them — and their firsthand experiences of HIV, have made them strong and resilient. Like Cecile and the organisation, they have become, through living testimony, a source of strength, knowledge and support to community members.

THE FIRST ON TREATMENT — ELIAS MABUZA

The story of Elias Mabuza, who, along with Caroline, Eva and Sipho, was amongst the first people to be counselled by the volunteer nurses at HAPG, reveals a great deal about the complexity of the HIV-virus as it entwined within the reality of contemporary South Africa. So often we hear stories of a mother’s love, but Elias’s story is about the absence of a mother and how this directed a large part of his life. And how his love for her led him full circle and helped him heal. He has come to play a protective role for those around him and for his mother, after living without her for 50 years.

Elias was born in Bela-Bela in 1948. His mother was South African and his father was from what was then Rhodesia (now Zimbabwe). When his father died, the three-year-old Elias, his siblings and his mother moved to Rhodesia to the paternal home near Salisbury (now Harare), which was the custom. His mother tried to adapt to the different way of life there, but she hated being so far away from her own community. She was eventually forced by the family to leave her infant son in the care of his uncle. Elias had a difficult life as he was moved between different members of the extended family. As a teenager, he wrote often to his mother but he never received a reply. It later transpired that his letters never arrived and he still wonders if the family ever posted them. For 50 years he had no contact with her whatsoever until in 1998, when he was struggling with TB, he sent her a final letter requesting to see her before he died. This letter arrived in Bela-Bela and triggered a response.

When he received a reply from his mother, telling him she was still alive and that if he wanted to visit he should do so, Elias was lying in bed, very sick. With financial help from a friend and with the support of his younger stepbrother he started making plans to return to South Africa. Elias had a criminal record in Zimbabwe, and was afraid he would not be allowed into South Africa. When he went to apply for the documents he required to travel to South Africa he had a battle on his hands as the government officials asserted that the letter from his mother was forged as it didn’t have a stamp on it. But, as he tells it, a woman “sent by God” interceded and helped Elias saying, “These things can happen to anyone, Elias” and he was given a temporary passport. Elias arrived in South Africa on 18 March 1998. He says, “When I came here, I went straight to get my South African identity document.”

When he finally found his mother, after all the intervening years, she recognised his son, despite the fact that he was sick and thin. He says, “She recognised me. She called me ‘boy’. Their reunion was extraordinary in many ways. In the five decades, the southern African sub-continent had changed dramatically, as democracy had reached Zimbabwe (in 1980) and South Africa (1994). The long-term challenges of under-development, a rapidly growing population, environmental change and threats from HIV and AIDS were beginning to undermine the optimism that had accompanied the arrival of democracy. Elias’s intention was to spend as much time with his mother as possible, but he feared the worst as his TB appeared to have returned. His earlier treatment in Zimbabwe had elicited a positive response but he had become seriously ill once again. At the Bela-Bela clinic he was re-tested for TB, with negative results, and Rebecca counselled him on taking a test for HIV. His result was positive, which explained immediately why the symptoms of TB had persisted. Apart from the counselling, Elias was only eligible for receiving food parcels, as there was no treatment available. Elias tells of the shame he initially felt when he learned that he was HIV positive: “When I was tested HIV positive I was told that this sickness is killing people and I thought it’s me who brought this sickness from Zimbabwe here. I felt very ashamed. Instead of coming here to join the support group, I went about the location [township]. I was afraid to tell my mother that I was HIV positive.” After a few months, Sister Rebecca suggested that Elias join the HAPG support group, which he did. Much of the support at this time was about how to look after oneself through eating nutritious food, using basic hygiene and care practices and seeking primary health care when necessary.

At this stage, Elias sought work as a gardener on a nearby farm, as he felt he would become a burden on his mother. The farmer instructed Elias to build his own house and dig a pit for his own toilet. As he started to dig the pit it began to feel like he was digging his own grave. He left the farm, returning to the township and the support group. Elias and Caroline laughingly shared this story. Elias began: “I still remember I got a job of a garden ‘boy’. And when I was going there, Caroline came with me. I said we are no more going to support group. Caroline said, ‘If you have got a job I am going with you.’ We were put into a ‘funeral van’; I said to Caroline Wh, these people can put us in a funeral van before we die.”

Caroline explained further: “Mabuza [Elias] was going for the job and she told me, ‘I am going to see where he is going to work. But inside me I was saying because Mabuza has left I am no more going to the support group. I will stay at home and I will go and visit him where he is working.’”

Elias continued: “So when I arrive there, they had a house and everything, and in the house there was a toilet inside. [But] I was told to dig my own toilet. And I was told that it must be six feet. So I started digging. halfway I said ‘to myself’ no, it seems like I’m digging my own grave. I came with a funeral car... after all, a grave is six feet — I was thinking — a grave is six feet! Meaning ‘I’m digging my own grave. I said no. I left all the tools there. I came by the place of Caroline. I said ‘No, I can’t do this. Tomorrow I am going to the support group’.”

Caroline adds, “Yes, he came to me at around one o’clock and said, ‘Caroline, no, I’m no more going there. It’s better tomorrow we go back to the support group’, and I say ‘Okay, then tomorrow we go back’. And... we came back here.”

Despite the group’s support, Elias slipped into depression and started to use alcohol heavily, seeking distraction from the “inevitable” end to his life. The shame he was experiencing meant that he felt he could not tell his mother. Elias considered suicide as his only real option. He carefully selected a tree near the entrance to the township where he would hang himself. As he walked to what he thought was his death he met Rebecca who, on realising what his intention was, persuaded him to take a different journey. In the support group, two members, one of whom was Caroline, were living openly with HIV. These two members convinced Elias that his depression was a result of hiding his HIV positive status and living with a sense of shame. It was with their help that he plucked up the courage to disclose his status to his mother.
He says, “I knew now how to live with it. I didn’t care anymore … Caroline made me be open with my status. I had the courage to live.”

They suggested that they accompany him to his mother, he agreed, and they initially engaged her about their own statuses, explaining that if they were able to live with evident health, would she “throw away” her son if he was also HIV positive? She immediately embraced Elias, promising her support, and exclaiming that there was no way she would disown him after already enduring 50 years of loss. Through their care and support, Rebecca, Elias’s support-group colleagues and his mother saved his life.

His full involvement in the support group allowed Elias to begin to realise that there was much to live for. He took on the responsibility of running the food garden, claiming that as he had grown up in Zimbabwe, he knew far more about gardening than South Africans. He promoted the importance of eating nutritious foods from a diversity of types and sources, arguing that people living with HIV would become stronger with careful nutrition. He was extremely thin when he spoke out about his status, which provoked much amusement from people who saw him as the stereotype “AIDS patient”, and a “stickman close to death”. People initially identified him as “one of those people of AIDS” who would soon die. When Elias and the support group members conducted their awareness training they were often mocked. Elias recalls a group of boys who told him that he would be dead by 2004; that even if he was taking medication, it would be of no use. But as time went on, they saw he was still alive. The cruelty of stigma became a source of strength, as Elias decided to defy the detractors and live as best he could with what time he had left. The support group gave him the meaning and ability to do so. With his mother’s acceptance of his status; the knowledge that HIV and AIDS are not the same thing, and that being infected with a virus is very different to being sick with a disease, Elias became a “new” person and he was able to open up to the community. These events marked a turning point for Elias, and ever since then he has been one of the most loyal members of the support group.

Elias and the other members of that initial support group went on to become much sought after HIV Counselling and Testing (HCT) counsellors, with people seeking them out at the clinic and after hours. At HAPG, Elias is a much loved character; the other counsellors affectionately call him ‘Zaza’ (Sugar Daddy) and he is regarded as a father figure by many. Elias’s honesty is touching and refreshing. He understands that it is his openness that is his gift. It took him a long time to accept this though. He believes that it is the courage and openness of all the members that is the gift they give to others living with HIV and to the many people who seek their help at the clinic. “…That’s why I became a counsellor. So others could see, through me” he says. As such a successful counsellor, his imminent retirement as he reaches the age of 65 is of some concern, however, the HAPG board and leadership have asked him to stay on as long as he wishes. He remains the counsellor most in demand.

Aside from the supportive role he plays at HAPG, Elias takes pride and joy in his relationship with his mother. Now that he has her back in his life he cherishes her and takes care of her. He cooks for her and supports her. Elias recalls how he used to frequent shebeens (taverns), take drugs and even sell drugs for a living. He seems to find it hard to believe he is that same person. He says, “I say thanks to Cecile and Rebecca and Caroline, and those who helped me to come
here to see my mother and to help my mother. I thank God for sending me here to my mother; for sending me to meet with people in this project; to change my life.” He adds, “Back home – with my mother and a life on top of it!”

The story of Lydia Pole, who was the general coordinator of the support group in the early days, provides another fascinating glimpse into how HAPG evolved into a successful programme, underpinned by individuals who in some cases had experienced life-saving transformations. When thinking back to the first generation of HAPG members, Cecile says of Lydia: “She is special. She was with us since 1999, as a member of the support group. After training as a counsellor, she began working at the hospital, and when we grew, she came to help me with daily administration as well as leading the team in Bela-Bela.”

Lydia joined HAPG after she was diagnosed with HIV. She recalls, “I was one of the members of the support group – in the end there were only four of us. We are friends up until today, and when we see each other, we understand each other.” It was Lydia who, along with other members of the support group, began the first community gardens, which continue to provide vegetables for many people today. Lydia says she loved her work because she found that both young and old came to her with their problems, and she loved to be able to help them.

THE NAMIBIANS OF VINGERKRAAL AND HILARIA SIMON

Hilaria Simon tells a harrowing story that reveals another dimension of the HIV epidemic in southern Africa. Hilaria, a Namibian by birth, came to Bela-Bela in the late 1980s when a large number of Koevoet soldiers were settled in Limpopo as Namibian independence from South Africa became imminent. Many of the soldiers brought their wives and families. The South African government had agreed to settle the soldiers because the incoming liberation government under the South West Africa People’s Organisation (SWAPO) regarded them as traitors and as war criminals due to their role as Askari – soldiers fighting on the side of the apartheid forces. In 1980, they were demobilized and as they could not be repatriated to Namibia they were granted South African pensions. In the late 1980s and early 1990s some of these soldiers were deployed in the internecine war between the African National Congress (ANC) and the Inkatha Freedom Party (IFP) in KwaZulu-Natal. These soldiers were used to “manage” the conflict that was unfolding during the lead up to the first democratic election. After a major drought in 1992, which contributed to the closure of a large number of farms, the soldiers pooled their money to purchase a farm, called “Vingerkraal”, in the Mabula area, 45 km from Bela-Bela. Initially the new owners disliked the name Vingerkraal, and instead used “Mabula”, but by the time they began to work with HAPG they had reverted to using the old name.

The members of the community of Vingerkraal, as it became known, were separated by language and ethnic identity from the broader communities amongst which they lived. Compounding this isolation was their choosing to remove themselves to their farm to establish their own community. As soldiers fighting for long periods away from home, many of the men had been exposed to HIV. The virus took hold and spread at an unprecedented rate within the closed community. The complex combination of denial and minimal awareness, a lack of health infrastructure and an absence of treatment meant that the community of approximately 3,500 people was reduced by 1,000 premature deaths within a decade. This attrition reveals in stark detail how AIDS can decimate a population living in denial and with limited resources. Largely because of the lack of access to water and other amenities, a group of families (13 initially) eventually moved from Vingerkraal to take up residence in government-allocated houses in Masakhane township outside Bela-Bela.

Hilaria was personally affected by the HIV and AIDS epidemic in 2004. Her sister died, leaving three children who were very sick. Hilaria took the children to the mobile clinic in Vingerkraal where the nursing sister advised her to take them to HAPG. Two of the children, one ten-years-old and the other five-years-old, were found to be HIV positive, and the younger child subsequently died. Hilaria and her husband raised the two surviving children, who are now young adults, along with their own five children.

Cecile says: “Before Hilaria came there was a very severe stigma at Vingerkraal, and people didn’t want to talk about HIV – despite daily (AIDS-related) deaths and an (HIV) infection rate close to 75% in the early 1990s. She came with the first group to our clinic and then, when we started working with the community, she got them together and motivated and helped with addressing stigma. People in Vingerkraal don’t even worry about stigma nowadays.”

One of the biggest difficulties for the ex-Namibians who settled in the area was their inability to speak the local languages. This added an extra burden to people needing any kind of assistance, especially medical help. Being a natural leader, Hilaria was the person community members turned to when the HIV and AIDS epidemic hit. She would accompany any community member who needed her support, to translate as well as counsel. When HAPG started working in Vingerkraal, the community suggested her as their representative. She became HAPG’s home-based carer in the area until she moved to Masakhane in 2009. Despite the difficulties she experienced in Masakhane as an “outsider”, she persevered and is now leading home-based care services in the area.
Fear of the unknown and the harsh stigma associated with HIV and AIDS were not the only threats facing the effectiveness of HAPG. In 1999, Thabo Mbeki became president of South Africa and so began a very challenging period in the history of the country’s response to HIV and AIDS. President Mbeki was an AIDS “sceptic” whose denialism had severe and often deadly implications. He questioned whether HIV played a part in AIDS (generally the sceptics tended to claim that HIV was a harmless retrovirus) and believed that the emerging antiretroviral drugs (ARVs) were toxic to those taking them and were being promoted to enrich pharmaceutical companies. This was immensely frustrating for HAPG and Cecile in particular, in light of the biomedical breakthrough that had taken place in the United States back in 1996. AIDS clinician David Ho and his colleagues had showed that “highly active antiretroviral treatment” (HAART) halted the replication of the HI-virus and its administration to an infected person led to what was often called the “Lazarus-effect” with the seemingly mortally ill rising from their deathbeds.

By questioning the connection between HIV and AIDS, and by arguing that corporations promoted ARVs for their own benefit, Mbeki essentially blocked an approach that could have saved tens of thousands of lives.

Up to early 2003, Mbeki’s doubts were the bedrock of national health policy. His Minister of Health refused to roll out a programme to distribute ARVs despite mounting evidence, advocacy, and national and international pressure. The messages articulated from national government, cascading through the spheres of provincial and district health, were confused and angry: the drugs were toxic and could not help people with an empty stomach; they were part of a plot for big business to make money. ARVs became cloaked in suspicion, and coloured by conspiracy. This shadow fell across Cecile, as she and a long-time colleague and friend, Dr Norbert Ndjeka, were accused, through whispers emanating from the Department of Health, of wanting no more than to test dubious drugs on black South Africans.

According to Dr Ndjeka, when antiretroviral treatment failed to arrive in South Africa, “We [at HAPG] didn’t wait for the national minister to see the need, as we recognised that the political situation was unlikely to change under the Mbeki administration.” Understanding the power of ARVs, Cecile began to access funding from Belgium to enable HAPG to dispense the medication to a few members of staff living with HIV. In 1999, Dr Ndjeka had studied Health Service Management at the University of Witwatersrand Health School, which was followed by a course in Family Medicine in 2000. Together with his Diploma in Tropical Medicine, Dr Ndjeka had gained a broad understanding of ARVs as the core to responding to HIV and AIDS in South Africa. Without them, he realised “families in Bela-Bela would continue to bury someone every weekend”. Cecile and Dr Ndjeka realised the “illegality” of their actions, but they did what they could to provide treatment for people that required it. The desire to save lives preceded concerns that Dr Ndjeka may have had about a career path in public administration. Indeed, Dr Ndjeka had been warned by colleagues within the Department of Health that he was going out on a limb in supporting HAPG in providing ARVs to people who were HIV positive.
this time it was regarded as politically unacceptable, as people were afraid to contradict the Health Minister, Dr. Mantombazana (Manto) Tshabalala-Msimang, who shared Mbeki’s denialist views. As a result, Dr Ndjeka believes he was overlooked for a senior health services position in North West province. Rumours abounded that he was under investigation by the Department of Health and he was warned by colleagues not to speak too openly about his work with ARVs.

When HAPG introduced ARVs to the community in 2003, the medication was surrounded by mystery. People feared them and rumours abounded. Elias Mabuza, as a member of HAPG’s support group, was the first to go on treatment. He volunteered to do so as he was the oldest amongst the support group and he felt that he was going to die soon anyway. He argued that if he survived then the treatment should be safe. Sophy laughingly shared her recollection of those stressful times: “... the ARVs were not here – the government didn’t issue them [but] we got them [...]. We were three: myself, Caroline and Elias, and we were saying, ‘Who’s going to start first?’ because [at] that time they were saying the ARVs are killing people; when you take ARVs you are going to die .... lots of things. And then Elias said ‘I’m the biggest [oldest] one. I’ll start, but if you see I’m alive you must start also.’ Then Elias started and we see one week pass .... Elias is very strong. Three weeks, Elias is VERY strong, he’s riding a bicycle, he’s doing the garden. Then I say, ‘I’m going to start.’ My CD 4 was 81. So we called Elias number one; I am number two and Caroline is number three.” While the support group members talk about this jokingly now, it was a momentous step for Elias to have taken. On 2 May 2013, Elias celebrated twelve years of taking ARVs; remarking to Cecile that “the Belgians have kept them – the government didn’t issue them but we got them … We were opened up. We had already been pioneering this method of dispensing treatment for almost a decade. In 2010 further progress was made with the initiation of wide-scale treatment through support groups that were intended to provide the basis for the government programme. Unfortunately many of these groups failed to be effective because they followed a set plan and did not always make adequate provision for the development of the trust-based relationships that are so necessary to sustain such groups. This was in stark contrast to how HAPG’s processes had unfolded. HAPG had already demonstrated the effectiveness of recruiting lay persons who were then trained to perform voluntary counselling and testing, establish support groups for PLHIV and people taking ARVs, and monitor adherence to treatment; in other words, treatment was given a public face. Cecile attributes HAPG’s success to the fact that, as she puts it: “We always did ‘with the community’, never ‘for the community’. If we want to do things, we have to talk about it. The more you open up, the less you want to do things in secret, and the fewer questions there are.” She adds: “When our patients started in support groups we gave them flow charts which they gave the doctor to fill in. We explained how they work and this gives them a sense of power. They know what is going on with them.” Cecile believes that having staff members in the programme who are living with HIV makes a difference because “they know what it’s like and want to do the same for others”.

The Wellness Clinic and its activities have created a strong network around patients through formal and informal relationships. Patients make use of the medical care provided and the social relationships established with caregivers, counsellors, other patients and support group structures. The medical doctor and the ART programme also played a role in building these relationships. They suggested that we should have a selection committee that would consider individual cases without knowing their identity. The composition of the committee was agreed upon, and it started meeting every second week to review and decide on the cases. Then we started with the treatment, and after two years there were hardly any deaths anymore. Our orphan numbers started to drop – we had only 30 orphans in the whole of 2008. We had less to engage with there, but now there were needed space for home-based care and we were getting very busy with the treatment programme. So we refrained our home–based carers to follow up on treatment adherence, and a community drop-in centre took over the orphan care.” By 2010, there was not one orphan that needed support. This is the extraordinary impact of antiretroviral treatment and positive living.

Along with the combined services of counselling, treatment and on–going care, HAPG began to offer workplace HIV screening and testing. Recognising that people worked irregular hours in the hospitality industry (an important source of employment in the area) and that a flexible way of doing things is appropriate to people’s lives, these services were made available after work and during weekends. Thus, at hotels and resorts around Bela-Bela, staff in large numbers were able to access treatment and care.

The South African government’s “HIV & AIDS and STI Strategic Plan for South Africa 2007-2011”, which was approved by cabinet in May 2007, brought momentous changes. One of its goals was to bring treatment to three–quarters of those who needed it, largely through nurses in clinics dispensing treatment and not doctors in hospitals. At that stage HAPG had already been pioneering this method of dispensing treatment for almost a decade. In 2010 further progress was made with the initiation of wide-scale treatment through support groups that were intended to provide the basis for the government programme. Unfortunately many of these groups failed to be effective because they followed a set plan and did not always make adequate provision for the development of the trust-based relationships that are so necessary to sustain such groups. This was in stark contrast to how HAPG’s processes had unfolded. HAPG had already demonstrated the effectiveness of recruiting lay persons who were then trained to perform voluntary counselling and testing, establish support groups for PLHIV and people taking ARVs, and monitor adherence to treatment; in other words, treatment was given a public face. Cecile attributes HAPG’s success to the fact that, as she puts it: “We always did ‘with the community’, never ‘for the community’. If we want to do things, we have to talk about it. The more you open up, the less you want to do things in secret, and the fewer questions there are.” She adds: “When our patients started in support groups we gave them flow charts which they gave the doctor to fill in. We explained how they work and this gives them a sense of power. They know what is going on with them.” Cecile believes that having staff members in the programme who are living with HIV makes a difference because “they know what it’s like and want to do the same for others”.

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It is easy to imagine that Dr Norbert Ndjeka’s relationship with Cecile was predestined. Their partnership has resulted in the saving of very many lives, and their courage and tenacity has resulted in an organisation that has led the way in offering real care to people. When they are seen together, the two are like an inseparable mother and son, but they probably seem more like angels to the many people in Bela-Bela who have benefited from their work.

Norbert Ndjeka was born in the Democratic Republic of Congo to a big “typical African family” with both parents from teaching backgrounds. On leaving school, he says there were always only three choices of study for him, “medicine, medicine and medicine!” He attended the medical school at the University of Kinshasa, an affiliate of Leuven University in Belgium, and affectionately called “Small Leuven”. After coming to South Africa in 1991 to study and work he finally arrived in Bela-Bela in 1999 as the first black Senior Medical Superintendent at the hospital.

Dr Ndjeka found a spiritual home in HAPG and a connection with Cecile. Together they worked towards building a constructive and effective response to the impact of HIV on the community of Bela-Bela. As his confidence in the clinic grew, Dr Ndjeka brought in other doctors to assist once a month, including a dermatologist, an ophthalmologist, a gynaecologist and an internal medicine specialist.

Perhaps even more significant, though, than Dr Ndjeka’s achievements as a doctor and with HAPG, is his attitude towards people. Sophy Maoka relates a special story that illustrates his kind and generous nature as well as his commitment to the wellbeing of others:

“In 2009 – I think – I fell pregnant. And I was not okay, I was still weak. Then the doctor said my body is not going to be able to carry the baby ... When I got to the hospital they admitted me (to perform an abortion). The following day they discharged me and said, ‘No there’s nothing we can do for you here. Just go back home.’ Then I came here and told Dr Ndjeka ... Dr Ndjeka went there (to challenge them). He said I’ll go with you ... Dr Ndjeka was next to me; he sat next to me. I was having so much pain. Then he said, ‘Hey Sophy I’m going to get something to eat.’ I said, ‘No you can’t go now, stay here with me.’ He said, ‘But I’m hungry.’ I said, ‘No sit!’ Then he said, ‘Please give me five minutes, I’m coming back.’ And I said, ‘Okay, five minutes.’ Then he ran quickly and said, ‘I’m back.’ And I said, ‘Sit!’

I found that if he’s sitting next to me the pain was much better.”

Cecile and Dr Ndjeka first came into contact when she was recommended as a potential member for the hospital board that he was setting up. She willingly agreed to join and he noticed both her knowledgeable input on HIV matters and how well she interacted with the other members. Being keen to do more work in clinics so that he could be closer to the community, he went regularly to the government clinic which is housed within the same property as the HAPG one. It was here that he saw her in a different context. He describes what happened, “So I would go to the clinics (including the one where HAPG is based) and Cecile started bringing patients; and after a few weeks I realised that files were lost all the time (in the government clinic). The clinic was poorly organised and I wanted to see the patients but it was...
difficult in an environment that was poorly organised. I also noticed that Cecile’s files were good ... and asked Cecile to have an agreement – she would help me with the [government clinic] filing system and I would see her patients.”

Working with the HAPG clinic meant confronting HIV head on. When it became clear that the South African government would not be able to distribute ARVs, Cecile sought support from Belgium so that they could at least offer ARVs to those HAPG team members who were living with HIV. Despite the “illegality” of their actions, together Cecile and Dr Ndjeka began administering ARVs to more and more people in Bela-Bela. Dr Ndjeka explains: “We started ARVs before it was legalised. We were convinced this was good. We were saving lives; I am a medical practitioner why should I be afraid to save lives. If we had listened [to the government] people like Elias [and] Caroline would have been dead by now.”

Dr Ndjeka believes that studying family medicine has built him as a doctor and that working with the team at HAPG has made him a better human being, more able to understand human suffering. He, Cecile, the nurses and the counsellors made a perfect fit; all were and remain committed to the wellbeing of the community and through this have been responsible for saving many lives.

**THE INTERACTION BETWEEN MEDICAL SCIENCE AND POLICY MAKING**

Although his responsibilities emphasised clinic work, Dr Ndjeka was also deeply committed to community health. He believed strongly in combining office work with practical engagement at grassroots and it was thanks to this that he quickly noticed the work that HAPG was doing. In many ways Dr Ndjeka’s career in South Africa has run in tandem with the growing success of HAPG. The relationship has been mutually reinforcing, and hearing his story also reveals a great deal about the wide impact that HAPG has made on policy and programme development in the country.

In the late 1990s, the primary health care processes across the public health sector were in disarray and required careful management. Dr Ndjeka, recognising that many of the government clinics were badly organised, used HAPG as a model to help systematise the way nursing staff and doctors engaged with patients. HAPG had developed a systematic approach to dealing with patients; there were proper patient files, clearly defined appointments, set dates for follow up, and results were carefully recorded. In an attempt to emulate the success of HAPG’s approach, Dr Ndjeka tried to instigate measures that moved away from “new pieces of paper being drafted at every consultation” to one where carefully managed documents and files ensured that medical practitioners could immediately see the condition of a patient. Essentially, this systematic approach was organised by Cecile who, for example, took it upon herself to organise the laboratory results so that everything was in place for the weekly consultations with patients.

From 2001, Cecile and her team had positioned HAPG to operate as an HIV clinic with the support groups, home-based care, support for orphaned and vulnerable children, and the broader awareness campaign revolving around it. In time, the provision of antiretroviral therapy and adherence counselling and mentoring was included. According to Dr Ndjeka, Cecile applied five basic principles to underpin this operation: awareness, prophylactic access, treatment of opportunistic infections, nutrition, and facilitating family support through home visits. Clearly Dr Ndjeka was inspired by this approach and recognised that behind the apparent simplicity was a comprehensive approach that was sorely lacking within his own institution. He realised that awareness was the central pivot of the comprehensive approach and that without it all other elements would fail.

In 2005, Cecile and Dr Ndjeka had an opportunity to consolidate HAPG’s work through a research paper that was presented at the International AIDS Conference held in Durban, South Africa. Here Dr Ndjeka presented an impact assessment of antiretroviral therapy on patients treated under HAPG. In many ways this was a key moment. Using data collected through the systematic service provided by HAPG, indisputable evidence was presented that showed that ART had a positive impact on those enrolled for treatment. The fact that treatment helped patients keep their jobs; reduced the need for health-care seeking behaviour; and improved their images within their families were powerful reasons for supporting the continued roll out of ART, which had started in 2004 in the public health sector. Despite indicating a desire to do so in 2004, it was only in 2008 that the provincial authorities in Limpopo province actually began the widespread roll out of the drugs. This was seven years after HAPG, and starkly reveals how much was lost due to the uncertainty created by misguided political leadership. The message from HAPG was that with the immense burden of HIV, treatment needed to be incorporated into primary health care. HAPG’s experience was that this was the most effective way of integrating treatment into a comprehensive approach that could effectively deal with the epidemic. The focus on primary health care began successfully in Limpopo in 2009 under the leadership of Aaron Motsoaledi, the then incoming Minister of Health.

HAPG had influenced beyond the HIV sector. In 2005, Dr Ndjeka was asked to help set up the new Multi-drug Resistant Tuberculosis (MDR-TB) unit in Limpopo, to deal with the powerful strain of TB that is resistant to the most potent first line anti-TB drugs available. He was chosen because he had worked on the complexities of HIV and held strong views on the interactions between this epidemic and resurgent TB. Limpopo was the only province at this time without such a unit and so he readily took up the challenge despite other work commitments. He was sent to Latvia in 2006 to gain experience in the interactions between TB and HIV and the management of them. The combined experiences of setting up the Limpopo unit, the Latvian field trip, a short period as the MDR-TB advisor at the University Research Co. and the years working in cooperation with HAPG meant Dr Ndjeka was the prime candidate to develop the MDR-TB policy for South Africa. He assumed a directorship at the National Department of Health in 2012 to develop such a framework. He continues to provide both practical and emotional support to HAPG through his role on its board as well as consultations in Bela-Bela over the weekends.

Through informal exchanges and networking, HAPG has shared its experiences and learnt from others, and by sharing its statistics, experiences and outcomes, HAPG has had some influence on policy.

It has worked in partnership with organisations doing research, including two South African universities, and these institutions then shared their research findings widely. Cecile gives the reduction in qualifying age for routine Pap tests (which are used to screen for cervical cancer) at government wellness clinics as one example of what has been
achieved by sharing HAPG’s results. This came about because HAPG initially offered a Pap test to every woman in its ART programme who was over 30 years old. As Cecile explained: “Everyone knows that HIV is a major risk for cancer of the cervix for women infected, but why do so many women still die of cancer of cervix in the country? All the women [in the HAPG treatment programme] do Pap smears as prescribed by the Department of Health and we treat them early enough and have not lost a patient to it; we pick it up early.” HAPG sharing its results with government led to the age level for routine Pap tests at government wellness clinics being reduced to 25.

In order to share the knowledge gleaned from the experiences at HAPG, various courses have been developed. These include courses on MDR-TB, developed by Dr Ndjeka before he joined the national department, skin diseases and cervical cancer. They are intended to be used by health care workers, medical practitioners and others.

Acknowledging the argument that decentralising care is critical, all are written in accessible, empowering language and aim to enable health care workers to increase their ability to manage the full spectrum of complications that accompany “new generation” infections.

ANOTHER PERSPECTIVE

Pascal Bessong is Professor of Microbiology in the Department of Microbiology at the University of Venda, and leads the university’s HIV/AIDS and Global Health Research Programme. Professor Bessong provides another important perspective on the impact of the carefully-collected data and analysis that HAPG has provided. He came to South Africa in 2000 to run a programme in microbiology, and once in the country also spent a lot of time at the National Institute of Communicable Diseases in Johannesburg. He first came across the work HAPG was doing in 2001, on a trip to Bela-Bela whilst pursuing his doctoral studies. At the time he was undertaking research on HIV and genetics to determine what was happening to the HIV-virus and whether new mutations were developing in parts of South Africa.

Of particular interest to him was the fact that HAPG had started an ART programme before most others. He was keen to learn about HAPG’s experiences and the outcomes it was seeing. He says, “As a virologist I was interested in seeing how the virus was responding to treatment. Clients were coming from around the Waterberg district. The idea was that treatment was going on for four to six years and we wanted to know how people were responding to drugs and drug resistance. We were also looking at those who were not on treatment; prevalence was still on the increase and we speculated that maybe if there is resistance development it may be transmitted to naïve populations. We did that study and found that the prevalence was very low, below the WHO threshold.” He and his team published their findings in 2005. They returned in 2006 to do further studies on the treatment programme and its effectiveness.

Professor Bessong acknowledges the important role that HAPG played for scientific research by it being the first to provide HIV positive people with access to ARVs in Limpopo. It had begun to provide treatment five years before government and had consistently collected data around the treatment and its effects on patients, including the results of blood tests, so this information provided a rich opportunity to undertake detailed research into whether resistance to the drugs was being developed by the virus. Two papers have been published from this study, both of which have had important implications for understanding the impact of the treatment on the structure of the virus. Fully tracking the influence that HAPG has had would be a study on its own, but what is already clear is that by ensuring a systemic commitment to accurate records, HAPG not only provides the best available service to its clients but also provides access to scientific data that can influence life-saving policy.

Apart from the scientific contribution, Professor Bessong also recognises the extraordinary dedication of the members of HAPG, including that of the doctors who volunteer on weekends, the commitment of the staff, and the unified vision of the group to play a role in the community, all linked to Cecile’s ability to follow through on a vision. He notes how this has been underpinned by the transparency with which the HAPG finances have been handled, and how every aspect of the running of HAPG has been meticulously recorded and reported.

In 2009/10 Professor Bessong accepted an invitation to become a member of the HAPG board. When asked why he believes that the HAPG clinic is so special he cites the courage shown by the staff, particularly when the South African government would not roll out ARVs; the fact that they were willing to talk about prevention issues and helped provide around-the-clock treatment and follow up; and the fact that the organisation doesn’t simply address HIV and AIDS in a conventional sense, but is also concerned with the treatment of side effects; the constant follow-up with patients, and the support given to patients.

A VIEW FROM THE HOSPITAL

Dr Juan-Carlos Rodriguez arrived in South Africa in 1996 as a member of the Cuban–South African government-to-government contract to provide medical practitioners, in particular doctors, to the fledgling democracy. As part of the first tranche of personnel, Dr Rodriguez was one of 400 doctors that were deployed across South Africa. He was sent to manage several medical wards at Hazview Hospital in Bushbuckridge (which was then part of Limpopo province). His immediate challenge was AIDS and TB. There was no ART available at this time, and he battled with the severe consequences of these epidemics. In 2003, he applied to move to Bela-Bela and was placed in charge of the medical wards at the hospital, in particular the intensive care unit. It was here that he first started to see patients on ARV in 2004. Dr Rodriguez was approached by Dr Ndjeka to assist with patients who were presenting with complications within the HAPG programme. In response, Dr Rodriguez started to visit the HAPG clinic on a monthly basis and immediately found the patients well treated and encouraged by the staff, who were genuinely concerned about the patients’ problems.

A view shared by many, and which continues to this day, was that patients who moved from the hospital to HAPG were better off with the attention they received.

Dr Rodriguez has tried to instil the lessons from HAPG into the public sector, to demonstrate how a systematically run project can provide a comprehensive approach to HIV.
Today Dr Rodriguez manages internal medicine at Bela-Bela Hospital (officially Warmbad/Warmbaths Hospital). He sees many young patients who have conditions that were generally associated with old age, but which are now occurring in people in their twenties. The occurrence of these conditions, which include hypertension, cancer, diabetes, heart failure and motor neuron diseases, is related to the HIV status of the patients; essentially, the chance of developing metabolic disorders increases the longer a person with HIV remains alive. When complications do occur in someone on treatment for HIV, it is important that a consultation to address the issue takes place swiftly. Dr Rodriguez believes that the number of patients seeking treatment for these types of HIV-related complications has increased dramatically since 2004 and he recognises this as the new frontier in the combating of HIV, and one that HAPG is addressing. Cecile and the other HAPG staff, being aware of this “new frontier” and the issues around it, ensure that early referrals are made. Dr Rodriguez acknowledges that HAPG is the only organisation he knows of that is alert to the need to deal promptly with these complications, largely due to Dr Ndjeka’s emphasis on family medicine. Conversely, the downfall in the public sector health system, reflects Dr Rodriguez, is that referrals never seem to take place. Although ARV guidelines that promote early referral have been available since April 2013, they are not yet widely available in public hospitals. In fact, it was only when Cecile copied and delivered the guidelines to the clinics and the hospital in the district that the staff in those institutions became aware of the existence of the guidelines. Once again, this underscores how important it is for those providing the services to remain ahead of the wave of issues that HIV brings, typically by reading the scientific literature. Although it is a philosophy shared and promoted by the Minister of Health, the challenges of inculcating this in the sector remain extreme.

Dr Rodriguez’s career in South Africa has taken him on a significant journey – from working with the epidemic at a time when treatment was unavailable to a point where there are not only modern drug regimes, but new complications emerging along with the extended lives that those modern drug regimes have made possible. These new challenges are exacerbated by problems of policy, administration and attitude. Sometimes the ability to meet a public good is denied as, for example, a life cannot be saved because a dialysis machine is not accessible. This is important in a context where HIV and AIDS will continue to be major burdens on the health system. Dr Rodriguez’s personal view is that up to 70% of the people that die at Bela-Bela Hospital (officially Warmbad/Warmbaths Hospital) are co-infected with HIV; nonetheless, he also articulates a positive view on the changes that have taken place over the last decade. He notes how in the “early days” people living with HIV were isolated in wards, whereas now they are more widely accepted by medical staff and the community. This transformation should be the basis from which the health sector goes forward to ensure that every patient has everything possible to be able to live a normal healthy life.

Dr Raul Fuentes, the head of gynaecology at Bela-Bela Hospital (officially Warmbad/Warmbaths Hospital), shares this view. He reiterated much of what his Cuban countryman and colleague had said, and also confirmed the complexities that they were beginning to face as the treatment regimes keep people alive for longer. Dr Fuentes believes that nurses in the public sector are coping much better now as they gain experience and follow the systems that have been developed; and that there has been a general improvement in the quality of treatment that the patients are receiving overall. He was careful when reflecting on the relationship between HAPG and the government, indicating that it was better not to get involved as a foreign doctor based in the public sector in South Africa. The complexities of
this relationship become clearer when looking at the interaction between HAPG and the District Health System. With the epidemic taking a new path of complexity, Dr Fuentes has committed to supporting HAPG as much as possible as his own specialist knowledge develops further.

A PRIMARY HEALTH CARE PRACTITIONER SPEAKS

Cathy Pistorius provides another important perspective on the relationship between the government and HAPG. Cathy had always felt strongly drawn to primary health care, particularly in rural areas, and as early as in 1996 she had become aware of the extent of HIV and the importance of primary health care in the fight against it. This is how she ended up as the Primary Health Care Manager of the then Bushveld region, which included Bela-Bela, Thabazimbi and Nylstroom (now Modimolle). She got to hear about the work of HAPG and was keen to learn more about what the organisation was doing and how it was being achieved. She met Cecile and, having decided that her region would have a focus on HIV and counselling, linked up with HAPG for it to provide training in counselling to all her staff. She says of this time, “This was in the beginning, when HIV was very stigmatised and people didn’t really want to talk about it. So I think that is where initially my relationship with Cecile started – to make sure that the staff members at [government] clinic level were aware of HIV, and knew how to counsel the people and how to care for them.”

Gradually she became involved in what HAPG was doing. Cecile’s ability to gain access to and share the knowledge she gained as the epidemic unfolded meant that she remained “ahead of the game” in terms of how to apply science in a practical manner. It was recognised that a focus on the community was important and that the best way to do this was to establish linkages with community-based organisations and non-governmental organisations (NGOs). In addition, these relationships would enable the sharing of data and analysis, which was necessary for an effective health service that would be responsive to the needs of the people.

Cathy’s department would team up with HAPG to do health promotion, primary health care and to share information. When the Bushveld and Western regions merged she became head of primary health care for Waterberg and decided that the staff in the western area should also be trained and educated. But this is when she met with resistance from the department. She says of this time, “This was in the beginning, when HIV was very stigmatised and people didn’t really want to talk about it. So I think that is where initially my relationship with HAPG started – to make sure that the staff members at [government] clinic level were aware of HIV, and knew how to counsel people and how to care for them.”

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Cathy believed that it was essential for the public sector to have clear linkages with NGOs, to build on complementary strengths and to share knowledge. She feels that, although senior department officials often appeared to share this view in public, promising to build linkages with NGOs, this seldom happened because, in reality, many felt threatened by civil society. She also believes that many officials resented expert opinion and that opportunities to influence government systems were therefore limited. Whilst she was head of the district, she felt she achieved a great deal in linking with NGOs and influencing relationships. It was at this time that Cecile asked Cathy to sit on the HAPG board and she happily agreed. For her, from a scientific point of view, the way the programme was being managed was having a positive impact on the community. She dearly wished for the work they were doing to be replicated throughout the region, especially the rural areas. She continued to serve on the board, despite resistance from the department. She rationalised that she was doing it free of charge and in her own time and in her personal capacity.

Looking beyond her part in the relationships between HAPG and the government-run entities in Bela-Bela, Cathy also played a considerable role in trying to establish another difficult connection – that between the churches in the township and the “white town”. Her approach was to try to enable people to understand what was happening in the community that they were not a part of, to help heal the rifts of centuries of separation and exploitation. This was very challenging for the white community, as HIV was not seen to be a part of their lives.

Gradually some came forward, recognising that the linkages needed to be built.

There continues to be a gradual improvement in consciousness through the advocacy that is being done. This is an area where Cecile has also been involved – through a "Women’s Forum" she has been able to talk to the "white congregations" about the relevance of the epidemic to them, and for the need to start building relationships with the people living in the townships.

Now retired, Cathy remains a member of the HAPG board and also volunteers once a month at the clinic, helping with taking blood. She is also on call whenever Cecile needs her. She believes that what makes HAPG so special is that people are listened to when they speak. She says: “You can have communication skills without having listening skills. That [to listen] is one thing Cecile teaches people. She even taught me that. To listen; to listen to what people say. And to me, that is the big difference. Whenever they want to talk about something that is troubling them it is not just shoved to one side.”

FACING FORMIDABLE ODDS

An important aspect of the way HAPG operates is that the organisation has never taken the initiative on behalf of the community; it might lead an activity for some time, as a facilitator, but would then encourage and assist the community to gradually take over the responsibility and ownership. Thus, by building community cohesion, social behaviour is adapted and strengthened. The power that this has instilled in the community was never more evident than when the government District Health Facility tried to take over HAPG.

According to several people, in 2009, circumstances led to the District Health Facility attempting to take over all aspects of HAPG’s work. The local community, led in particular by people living with HIV and receiving treatment from HAPG, mobilised and eventually forced the provincial government to reinstate HAPG’s right to continue to dispense treatment with government funding. The crisis started when international financial support from the United States President’s Emergency Plan for AIDS Relief (PEPFAR) was inexplicably withdrawn from HAPG and other civil society organisations throughout Africa. The situation was so severe that the HAPG Wellness Clinic had to be closed with
immediate effect. Cecile and the board approached the Catholic Bishop’s Conference, which administered PEPFAR funds in South Africa, raising the concern that several hundred people would now be without life-saving drugs. They were subsequently informed that they needed to make arrangements with the Limpopo Department of Health, and the situation then merged on the absurd.

Attempts at communication with the provincial authorities went unanswered. Using contacts made through HAPG board members, a meeting with the senior provincial officials was eventually set up. According to several staff members, the provincial officials were visibly impressed by the systems that HAPG had in place and set out to help to alleviate the situation. Subsequently, however, during a meeting arranged with the Bela-Bela Hospital (officially Warmbad/Warmbaths Hospital), Cecile was asked to wait outside and after two hours requested to enter and present HAPG’s “argument”. She was very surprised at the response. She was told that the Department of Health wanted to take over the HAPG Wellness Clinic and that all the HAPG patients had to be transferred to the Bela-Bela Wellness Clinic at the hospital. The Catholic Bishop’s Conference agreed to provide financial support to HAPG for three months to enable this transfer to take place. Further attempts to call district and local officials went unanswered.

The reaction of the community, led in particular by several patients who had been receiving treatment from HAPG, was one of dismay. This initial shock turned into an agitated protest when some of the patients experienced the poor service from the government facility. Along with their anger about the poor service, they were also angry at the lack of consultation and the provincial government’s attitude towards HAPG, which they saw as their own organisation. Most of the patients refused to move across to the government-run clinic, which forced the provincial department to engage a community liaison officer from the hospital. This officer tried to explain to the community that the government could not hand over its property to an NGO. Angered by this attitude, an organised protest began, led by the patients who told the government-run hospital that they “would rather go without treatment and die” than receive their treatment from it. The local police were called to attend to the protest and on hearing of the situation requested that the demonstrators act within the bounds of the law. Several policemen joined the protest when they went off duty. Despite the rising levels of anger, appeals to provincial officials received no response and a date of 1 June 2009 was determined to be the transfer date. District officials arrived to collect the patients’ files and confirmed that they would bring a clinic into the township within two weeks, and it would be situated near to the HAPG clinic. People remained unhappy. On the date of transfer, the promised doctors and nurses were not present to receive their new patients, and files had not been readied. Essentially, the provincial authorities had failed to respond to the community’s needs.

During this period, with the support of funds from Belgium and an Oxfam Deutschland grant, HAPG was able to retain 58 patients to enable them to receive treatment and care. These 58 patients were made up of HAPG staff and the most seriously ill people that the senior doctor had decided to continue involving during the transfer. Trying to rally its resources, HAPG began to rent premises in town where its staff could see to the needs of the most serious patients and continue with the distribution of what ARVs and laboratory tests they had. They also started to receive some of their previous patients from the clinic. Many of the patients wanted to come back, but HAPG was forbidden by the hospital to accept them. Patients using, or attempting to use, the government facilities complained that they were not receiving their treatment, that they had been refused routine blood tests to ascertain their CD4 counts, or if “lucky enough” to be given the tests, had received their results late and were generally treated with disdain by the nursing staff. Of the 480 patients from HAPG who were forced to transfer, 130 stopped treatment. The result was that many of them died within a year. The hospital remained unmoved, using the order from Polokwane, the provincial capital, to justify its refusal to allow HAPG to take back its patients. It seemed that the senior officials in the Department of Health in Limpopo had been threatened by the success of HAPG. One official remarked that under Cecile’s leadership, HAPG was “against the government”.

While all this turmoil was occurring, HAPG provided as much home-based care as it could coordinate, and continued with support groups. Large numbers of volunteers divided the township into manageable units, and went to see everyone on the HAPG lists to assess their situations. HAPG attempted to raise additional funds from CARE and from The Global Fund to Fight AIDS, Tuberculosis and Malaria. It was during discussions at the Helen Joseph Hospital in Johannesburg that Cecile started talking with the Ndlovu Trust, which was based in the Sekhukhune District of Limpopo with a satellite in the Waterberg District. In November 2009, the Ndlovu Trust invited Cecile to an AIDS Day Celebration to which they had also invited the HIV Programme Head in Limpopo Province, Dr William Shilumani. Unbeknown to Cecile, Ndlovu Trust had briefed Dr Shilumani in advance and thus facilitated a meeting between him and Cecile. On hearing the story, Dr Shilumani told Cecile that the initial correspondence from HAPG had never reached him. He confirmed that certain individuals in the province were likely to be behind what had happened to HAPG. At the AIDS Day Celebration, he committed to visiting Bela-Bela the following day, requesting that Cecile arrange a meeting with her staff and some of the HAPG clinic’s former patients. On his journey to Bela-Bela the next day, Dr Shilumani drove via the town of Modimolle and requested that the district officials accompany him to the meeting at HAPG. They refused, and Dr Shilumani arrived alone. When seated in the room with the HAPG staff, he requested of Cecile that she tell the story once again. He then asked the patients to verify the story, which they did. Dr Shilumani then quietly left HAPG and drove alone to Bela-Bela Hospital (officially Warmbad/Warmbaths Hospital), returning with the hospital’s chief executive officer and the medical doctor in charge of the Bela-Bela Wellness Clinic. He gave them instructions to make arrangements for HAPG to receive supplies of medication from the hospital, and said that the state would cover the costs of this medication, as well as the costs of the blood tests. Dr Shilumani requested that HAPG continue to cover the costs of its own doctors.

All patients who wanted to return to HAPG would be allowed to do so.

At the Third South African Tuberculosis Conference, held in 2012, four Limpopo-based presentations were made – one by Dr Ndjeka and three by Cecile. Dr Shilumani attended all four presentations, confirming his support once again for what HAPG was doing. He told Dr Ndjeka that he was disappointed that no other presentations had been made from the province, expressing frustration with his officials. He confirmed once again that the province would continue to pay for the treatment and blood tests, indicating that HAPG could rely on his support. He also confirmed that he

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would delegate funding for the payment of an additional nurse for the group, and this is being pursued by the HAPG Board. Unfortunately, tensions with the Waterberg District Department of Health continued. Dr Shilumani requested that a memorandum of understanding be established between HAPG and the Limpopo Government and forwarded the document to Cecile, requesting that she acquire a district signature. However, for over two years, district officials have refused to grant that signature. Nonetheless, the overriding message of this story is that when medicine and health care are delivered efficiently and with compassion, and ordinary people start realising it is their right to receive such a standard of care, then the politics of public health can eventually be overcome.

CONTRASTS – WHY HAPG WORKS

HAPG powerfully demonstrates how an effectively functioning clinic can be structured around a strict sequence of time-bound routines and systems of recording and reporting. Since ill health is extremely complex and highly variable, these strict routines must work to provide, concurrently, both the information base and the space for discretion and judgement based on the skill and experience of those providing the services.

The public health system in South Africa provides services that are largely found to be in stark contrast with the way HAPG functions. In an article published in 2010, Professor Karl von Holdt discussed “the workings of the post-apartheid South African state bureaucracy, within the state hospitals and provincial health departments, in an effort to understand the reasons for its poor functioning.” He writes that he and colleagues had found “over-centralisation, fragmentation into silo structures, low management capacity and understaffing were the primary causes of institutional stress and poor healthcare outcomes”, and these lead to what the doctors and nurses interviewed acknowledged as “poor clinical outcomes and higher levels of morbidity and mortality than ought to be the case”. The “culture of moving onwards and upwards” towards the next job prospect, rather than concentrating on improving the area the official is responsible for, and therefore the lot of the patient, also came under scrutiny. He states: “There is a high turnover of incumbents, and a significant number move out of the agency or department where they are located, making it difficult to create a stable body of expertise in the functioning of a specific department such as health.” (Professor Karl von Holdt is the Director of the Society, Work and Development Institute at the University of the Witwatersrand. The sections quoted in this paragraph are from his article entitled “Nationalism, Bureaucracy and the Developmental State: The South African Case”, which was published in the South African Review of Sociology, Volume 41, No. 1 2010. The article covers research findings made over a number of years by Professor von Holdt and colleagues.)

Dr Ndjeka’s comments about staffing echoed these sentiments. He indicated that within the last three years the government clinic at Bela-Bela had trebled its staff numbers yet still asserted that it could not cope. In his view it did not need more staff members, but rather needed to rearrange how it operated, with improvements in leadership and management style. Cecile confirmed that the Limpopo MDR-TB Unit was “turned around in six months” under Dr Ndjeka’s leadership, proving that effective delivery can be achieved in government-funded facilities.

SURROUNDED BY ACTIVISTS

The HAPG board members are carefully selected by the staff, based on their commitment to community development and their practical natures.

In keeping with the ethos of the organisation, the board members, and the other volunteers, are all activists in their own right and people on whom others can rely. Johan Adams, Professor Pascal Bessong, Alpheus Lealaka, Caroline Mabusela, Cecile Manhavee, Cathy Pistorius, Suzan (Suzy) Maswanganye, Dr Norbert Ndjeka and Petronella Ramolotja make up the current board. The stories showing how these dedicated people have contributed to and interacted with HAPG over the years are woven throughout this narrative. As this account draws nearer to a close we are privileged to share the stories of Johan Adams and Suzy Maswanganye, another two board members who have walked the long road with HAPG.

JOHAN ADAMS

Johan Adams has been principal of Spa Park Primary School for the last 23 years, joining the school as its youngest principal at the age of 22. As an educator in a disadvantaged community, he was well aware of the social problems the children were confronted with and set about working towards mitigating the impact these problems would have on the children, and building up the morale of the children. He instilled in his teachers the principle that they were in loco parentis – at school they were the parents of the children in the absence of their parents. He says he would say: “In the books they say, ‘You are the mother and the father in loco parentis’ – when the parents aren’t there. Let us practice it, let these children find a home. [They must feel] I can go there and for these eight hours, someone is going to take care of me.”

He also recognised that the children at his school could not be treated in the same way as those attending Laerskool Warmbad, another primary school that was situated in a more affluent area. It was attended by children whose parents could take time out to watch them play sport, and could afford to pay for excursions and educational activities. He says: “I said to the teachers, can we treat the children the same? No we can’t. Because 90% of the children at Laerskool Warmbad, their parents are the owners … the bosses ... where they are. Our parents are the subordinates and the workers. They don’t have the same privileges … Our parents can’t be there [at events] because they are working for those parents. So we can’t say we don’t get support from the parents because then we are forgetting the circumstances.”

Johan believes Spa Park was one of the first communities to experience the impact of HIV although they did not yet have a name for the constant infections, diarrhoea and other illnesses that indicated HIV-compromised immune systems. HAPG had begun working in Spa Park at this time. He says: “HAPG had started working this side and our school had been affected a lot – parents getting critically ill, not able to take care of children anymore; households disintegrated because parents were starting to die; grandparents taking care of children; and then child-headed households.” The school joined forces with HAPG, focusing on prevention.

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In Johan’s eyes, the things that make HAPG special are:

- A lack of politics: “There is no politics…. It doesn’t matter from which walk of life … I’m respected as a human being – finish and klaar.”
- Respect for privacy: “When people go into the room, secrecy is kept.
- The quality of the service: “Because of funding that we had here [at HAPG], we could provide things which you could not find in the government spaces. And people could see that we really cared … and continued to take care of families until they got their grants.”
- The annual AGM with the openness about funds available and how they’ve been used.
- Hard work: “That’s the other thing. You could find people like Cecile – they are hard workers. She’s always here. When a person calls her at one o clock in the morning, regardless of her own health – and there was a time when she almost lost it. She gave up her own health and that gave more impetus to peoples’ belief that she is serious about what she’s doing.”

In concluding, Johan says: “We wouldn’t like ‘the ship’ to run forever because if the ship does run forever then it means we failed … We want to reduce the numbers to the extent that there are no numbers any more. Then we can say, ‘a job well done’. In the period when it was necessary, this programme was necessary, and now we can look at other programmes.”

**SUZY MASWANGANYE**

Suzy Maswanganye has been working at Home Tekna – a place of safety for children in Bela-Bela – for the past 15 years, ever since she left school. Beginning as a cleaner, she first worked her way up to the job of caretaker and then, having completed a two-year course as a social auxiliary, she became a housemother. It is her job to supervise staff and she is responsible for the older children and babies.

Suzy is HIV positive and her openness about her status has meant that the children and others around her have felt they could talk to her about HIV. Suzy’s husband passed away in 2010, leaving her with their one son, who is studying chemical engineering. She says of her husband’s death, “It was very hard and very painful but I expected it; the doctors kept me informed and I asked if there was any chance. I accepted it and just tried to make the best life for myself.”

Suzy’s interaction with HAPG began when she would take children there, and she subsequently joined the HAPG support group. Being a member of the support group meant she got to know HAPG and the people there, and they also got to know her. They invited her to be a board member and she gladly accepted, she says she sees the role as an honour and a privilege.

She says of HAPG: “Oh, it’s very special … I’ve been involved in it since I took children from Home [Tekna] and I realised that the environment was welcoming.”
The stigma was rife then but with this organisation you were treated like a human being because people were not discriminated against.

I don’t know if it’s because people there were also HIV positive, but I felt warm and comfortable and at ease to disclose and accept.” When she found out about her status, HAPG is the first place she went. Suzy believes that HIV should not be a stumbling block to a happy life.

THE FUTURE

Having faced the challenges of establishing itself during the turmoil of the 1990s and early 2000s, the future for HAPG seems more certain, however the attempt by the District Health Facility to take over the clinic is a reminder that this confidence should be tempered. Generally speaking, however, HAPG has the support of the government clinic and is a safe place for everyone. There is a sense of confidence about the future, particularly regarding the support from organisations such as Oxfam and the ever-reliable Belgian funders. What is less clear is what a change of leadership will bring. Sister Winifred, for example, argues that the future of HAPG will depend to a large extent on the leadership position being held on an ongoing basis on by someone who is reliable and trusted by the community.

HAPG will continue to require careful day-to-day management and the information system, which has underpinned the effectiveness of the treatment regimes, will have to be maintained at its current high level.

Another reality is that HIV and AIDS will continue to be a presence into the future. People have not changed their behaviour so radically that the epidemic will be stopped in its tracks. Other conditions, some structural, that create an environment conducive to the spread of HIV remain in place. The prevalence of rape, compounded by alcohol and drug abuse, is increasing in Bela-Bela. Also, according to HAPG board members, Suzy Maswanganye and Johan Adams, drug abuse is becoming a major issue in the community, with many young, unemployed men believing that they can ascend the socio-economic ladder quickly by selling drugs. In addition, many of the young people have very low self-esteem, worsened by the lack of recreation facilities that might otherwise occupy their energy and focus. Many parents and young adults are absent, as they seek an income in the cities, leaving their young children in Bela-Bela with their grandparents. Although government services continue to improve, especially in the provision of better infrastructure for water and sanitation, often the need for them to be paid for makes them inaccessible to people without income.

Government grants are supporting many people, but such a safety net is not an adequate alternative to employment.

All of this relates to the challenge of how to keep abreast of the epidemic, a challenge that HAPG has had to negotiate continually over the last 20 years. With the burgeoning population, many more NGOs are going to be required to work with people and government to ensure ongoing development. From the outset HAPG has adopted an approach that uses community participation to ensure that beneficiaries guide the organisation in its initiatives; in its particular case its clients and patients are the ones that inform learning, reflection and planning. As an organisation firmly
committed to the people it serves, HAPG has adapted what it does through taking into account the results of research conducted by its own staff, in collaboration with universities in South Africa and abroad, as well as other studies. This has allowed the organisation to continue learning, reflecting, sharing and adjusting its interventions.

Final thoughts on the future of HAPG should consider the power of its social capital: with minimal staff and a team of dedicated volunteers, HAPG has administered ART to hundreds of patients in Bela-Bela.

This was only possible because HAPG had access to the social capital available within the local community. Many lay people, a considerable number of them living with HIV, have been the backbone of HAPG through their commitment to improve life for themselves and their community — their condition stimulates their commitment to help others. Training and experience has allowed them to build their own capacity for the sake of their community. It was this cohesion that saw off the threat of being taken over — and it will be this that will enable HAPG to face the new challenges as Bela-Bela transitions into the future.