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AIDS LEGAL NETWORK
A Publication of the AIDS Legal Network **March 2006**

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Realising Socio-Economic Rights in South Africa: A demand for constitutional challenges?

After a legacy of colonialism and Apartheid, South Africa, in 1994, became a democratic nation in which all its citizens were granted the right to participate in political life. The South African Constitution has been labelled as one of the most progressive, transformative and gender sensitive pieces of legislation in the world.

It enshrines the rights guaranteed to all, including political and civil rights and socio-economic rights. All of these rights are inter-related and mutually supporting. Affording socio-economic rights to all, enables people to enjoy the other rights enshrined in the Bill of Rights, Chapter 2 of the Constitution.[1]

In recent years, human rights bodies, like the United Nations, have stressed the need for the protection of socio-economic rights, especially for vulnerable groups, like women and children. Democracy and human rights, though distinct, are closely interlinked. Democracy, as a human right in itself, operates optimally when other human rights are respected, such as socio-economic rights. Democratic processes within a country can, arguably, suffer major setbacks when democracy falls short of their citizen's expectations, particularly in delivering development and alleviating poverty. For the purposes of this article, I will concentrate on unpacking the concept of socio-economic rights as provided for in South Africa's Constitution, and, thereafter, I will look briefly at Section 27(1) of the Constitution in relation to the right to have access to social security for people living with HIV and AIDS.

So, what does the term 'socio-economic rights' mean? In its most elementary meaning, socio-economic rights *'create entitlements to material conditions for human welfare – they are rights to things such as food, shelter, water, health care services etc'* [Brand, 2005:3][2] Some of the socio-economic rights, contained in the Constitution[3], are the right to a safe and healthy environment (Section 24); the right not to be deprived of property (Section 25); the right to have access to adequate housing (Section 26); the right to have access to healthcare, sufficient food, water and social security (Section 27); children's socio-economic rights (Section 28); the right to basic education (Section 29); and the right of everyone who is detained, including every sentenced prisoner, to be provided with adequate accommodation, nutrition, reading material and medical treatment (Section 35(2)(e)).

IMPOSING DUTIES AND ENTITLEMENTS ON THE STATE

According to Section 2 of the Constitution, the constitution imposes a duty on the state to fulfil all the obligations contained in the Constitution. This inevitably means that socio-economic rights form part of the obligations placed on the

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Editorial

A society must seek to ensure that the basic necessities of life are accessible to all if it is to be a society in which human dignity, freedom and equality are foundational. [Judgement in Khosa v The Department of Social Development, 2003]

It is the very access to *'the basic necessities of life'* for all that would define an adequate response to, and management of, the HIV and AIDS pandemic. Instead, inequalities, poverty, unemployment and destitution due to, and in the context of, HIV and AIDS seem to be ever-increasing; access to socio-economic rights remains limited due to *'available resources'*, and the constitutional guarantee to enjoy all rights and freedoms seems to remain but a dream. The ones most vulnerable and in need of access to *'the basic necessities of life'* are the ones who often remain excluded and, thus, the ones who are increasingly impacted and affected by the pandemic.

It is within this context of the correlation of poverty and the HIV and AIDS pandemic that this issue of the *ALQ* focuses on the access to socio-economic rights in the context of HIV and AIDS. The various articles in this issue examine the extent to which various socio-economic rights are accessible and realisable, and, thus, provide access to *'the basic necessities of life'* for the ones most vulnerable and marginalised, and for people living with, and affected by, HIV and AIDS. The meaning and concept of socio-economic rights, the judicial enforcement of socio-economic rights, and the interrelation of socio-economic rights and civil and political rights, as well as refugee's exclusion from accessing social assistance, poor people's access to healthcare, the dilemma of *'choice'* between ARV and social assistance, and prisoners' lack of access to treatment are some of the issues explored in this edition. This issue also includes a discussion on the challenges of home-based care volunteers, as well as an introduction to *'Khabzela'*. The integral features of the *ALQ* introduce HIV and AIDS realities and challenges from Malawi, and the experiences of Nkomazi, a rural community east of Nelspruit, Mpumalanga, trying to respond to the realities and challenges of the pandemic.

In this issue, **Urvarshi Rajcoomar** explores the meaning and concept of socio-economic rights, as provided for in the Constitution, and the role and competency of the judiciary in enforcing socio-economic rights in South Africa. Analysing various examples of judicial enforcement of socio-economic rights and examining the extent to which access to social security can be realised by people living with HIV and AIDS, she argues that more constitutional challenges are needed so as to ensure that people who are poor and in need are no longer excluded from access to, and realisation of, socio-economic rights.

Recognising the inability of the DCS to provide anti-retroviral treatment (ART) to prisoners, **Lukas Muntingh** raises the question whether or not medical parole could be a means for prisoners to access ART. Analysing legislative provisions in relation to medical parole and prisoners' right of access to healthcare, he argues that medical parole provisions are not there to address shortcomings in the prison system and, thus, the state has an inescapable duty to provide qualifying prisoners with access to ART, without compromising their health further.

The interrelation of socio-economic rights and civil and political rights is explored by **Shawn Hattingh**. Exploring the differences between these rights, he raises the question as to whether or not civil and political rights can be enjoyed, if there is limited access to socio-economic rights and argues that true equality cannot be achieved without the full recognition, realisation and enjoyment of civil, political and socio-economic rights.

Acknowledging the fact that refugees living with a disability are excluded from accessing social assistance, **Fritz Gaerdes** raises the question whether or not the exclusion of the most vulnerable is justifiable. He examines various constitutional provisions, current and new legislative provisions, as well as state obligation in terms of international law, and argues that the continuous exclusion of refugees living with a disability from accessing the Disability Grant is not only morally and ethically unjustifiable, but may also be unconstitutional and, thus, challengeable.

The realisation of the right of access to healthcare is argued to be one of the pre-requisite for an adequate response to, and management of, the HIV and AIDS pandemic. **Bryge Wachipa** discusses the implications of judicial enforcements of the right to access healthcare and argues, that while litigation is an important tool to realise socio-economic rights, it does not afford adequate access to healthcare for the poor and most vulnerable people living with HIV and AIDS.

The anti-retroviral therapy programme in Lusikisiki

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state to fulfil. Furthermore, Section 7(2) speaks of the state respecting, protecting, promoting and fulfilling the rights as contained in the Bill of Rights. It is imperative that, when assessing what duties and entitlements are imposed on the state, one must look at the nature of the right in question.

It is submitted that socio-economic rights can be classified into three groups:

Group 1 – the ***'qualified socio-economic rights'*** impose a positive duty on the state, and are commonly identified as *'access'* rights. These rights place a positive duty on the state to *'take reasonable steps within its available resources, to achieve their progressive realisation'*. Examples of qualified socio-economic rights are everyone's right to have *'access'* to adequate housing (Section 26(1)), and everyone's right to have *'access'* to healthcare, sufficient food, water and social security (Section 27(1)). The positive duty imposed on the state is expressly stated in Section 26(2) and Section 27(2) – *the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.*

This stance signalled the Constitutional Court's reluctance of undertaking its new mandate of being a watchdog to socio-economic rights in South Africa.

Group 2 – the ***'basic socio-economic rights'*** [4] are neither formulated as *'access'* rights, nor are they subjected to the qualifications of *'reasonableness'*, *'available resources'* and '*progressive realisation'*.[5] These rights include the right to basic education, including adult basic education (Section 29(1)(a)), and every child's right to basic nutrition, shelter, health care services and social services (Section 28(1)(c)).

Group 3 – according to Brand [2005:4][6],

> *These rights are formulated as prohibitions of certain forms of conduct, rather than rights to particular things e.g. S26 (3) prohibits arbitrary evictions and S 27(3) prohibits the refusal of emergency treatment. These 2 rights are also not explicitly subjected to any of the special qualifications that are typically attached to 'qualified socio-economic rights'.*

THE JUDICIAL ENFORCEMENT OF SOCIO–ECONOMIC RIGHTS IN SOUTH AFRICA

We live in a society in which there are great disparities of wealth. Millions of people are living in deplorable conditions and in great poverty. There is a high level of unemployment, inadequate social security, and many do not have access to clean water or to adequate health services. These conditions already existed, when the South African Constitution was adopted, and a commitment to address them, and to transform society, so that there will be human dignity, freedom and equality, lies at the heart of South Africa's new constitutional order. However, for as long as these conditions continue to exist, this aspiration will have a hollow ring.[7]

One might ask how socio-economic rights can be transformed into legally enforceable entitlements that advance social justice. It has been said that the ultimate test of giving constitutional recognition to these rights is whether or not they result in real improvements in the quality of life for all.[8] Debates on the justiciability[9] of socio-economic rights have been raging on for years between many legal academics and was effectively laid to rest in *Government of the Republic of South Africa and others v Grootboom* [10].

The first socio-economic rights case to come before the Constitutional Court was *Soobramoney v Minister of Health, KwaZulu Natal* [11]. Even though it did not settle the debate on the justiciability of socio-economic rights in South Africa, it was fundamental in setting the stage for engaging the judiciary, whose primary role is to be the protector and enforcer of all rights. The applicant in this case, Mr. Soobramoney, suffered from chronic renal failure, which required, for his survival, regular kidney dialysis treatment. He did not have the resources to obtain treatment from private sources and approached a state hospital for the provision of the treatment, but was refused. The rationale for refusing Mr. Soobramoney treatment was based on the fact that dialysis treatment was expensive, and resources within that hospital were limited. Therefore, a policy to limit the number of patients who would qualify for dialysis treatment was developed by the hospital.

Mr. Soobramoney, after being unsuccessful at the Durban and Coast Local Division of the High Court, approached the Constitutional Court on the basis that his right to receive emergency medical treatment (Section 27(3)) was being infringed. The Court stated that it would *'be slow to interfere with rational decisions taken in good faith by the political organs and medical authorities whose responsibility it is to deal with such matters'* [12]. Accordingly, the Constitutional Court declined to overturn the decision to refuse treatment to Soobramoney.

It is worth noting that the Court, in this case, was reluctant to interfere in the decisions made by political organs and did not want to trespass into the territory of the resource allocation. This stance signalled the Constitutional Court's reluctance of undertaking its new mandate of being a watchdog to socio-economic rights in South Africa.

However, in *Government of the Republic*

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is introduced by **Hermann Reuter**. Sharing experiences of the programme and exploring the arguments of clinic-based ARVs versus *'down referral'*, he argues that it is through the approach of decentralising initiation of ARVs, that the uptake can be increased rapidly and the loss to follow-up be reduced.

In the context of high levels of poverty, unemployment and HIV prevalence, **Susie Clark** introduces the dichotomy of social assistance and anti-retroviral treatment. Considering that the Disability Grant is often the only household income, she argues that while access to ARVs provides the possibility for a longer life, it presents a dilemma, since people living with HIV might have to choose between accessing social assistance and, thus, provide 'income', or accessing treatment and, thus, potentially loosing the only form of income of the household.

Nkomazi, a rural community east of Nelspruit, Mpumalanga, is introduced by **Heather McKillan**. She examines various realities and challenges of Nkomazi – a community, greatly affected by not only high rates of unemployment, poverty, inequalities and abuse, but also by high HIV infection rates – and argues that despite the harsh and 'morbid' realities of Nkomazi, there is hope due to the capacity of the human spirit to overcome this.

Faustace Chirwa introduces HIV and AIDS realities and challenges in Malawi. Providing an overview of the pandemic and analysing the successes and obstacles of treatment initiatives, she argues that there is a *'light at the end of the tunnel'*, despite the lack of innovative interventions aimed at speedy sexual behaviour change, the challenges of *'fake drugs'*, and cultural practices that exacerbate the spread of HIV and AIDS.

Looking at the repercussions of armed conflicts, **Kabir Bavikatte** is *'making a point'* about HIV and AIDS amongst conflict affected and displaced populations. He explores the direct and indirect effects of conflict on the spread of HIV and argues that while preventive measures tend to be limited in conflict situations, a lot more could, and should, be done to effectively combat the scale of HIV infection amongst conflict affected populations.

Examining the meaning and concept of socio-economic rights, their judicial enforcement, and the various realities of vulnerable, poor and marginalised people accessing socio-economic rights, it seems that while the continuous lack of adequate access might not be necessarily morally and ethically justifiable, it is, however, to an extent, justifiable within the constitutional realm. The recurring argument seems to be that the constitutional provisions of *'access to'*, as compared to *'the right to'*, socio-economic rights, and of *'progressive realisation'*, which is defined by *'available resources'*, and not by the need to *'basic necessities of life'*, will ultimately continue to define the extent to which the most vulnerable, marginalised and in need are in the position to access, claim and enjoy socio-economic rights – and this even with the role and competency of the judiciary to enforce the access to, and realisation of, socio-economic rights for all. Thus, despite the recognition that a society based on principles of human dignity, freedom and equality needs to *'seek to ensure that the basic necessities of life are accessible to all',* the most vulnerable, poor and marginalised people of society will continue to be excluded from accessing the very same *'basic necessities of life'*.

If we are to agree that fundamental principles of human dignity, freedom and equality can only be enjoyed to the extent to which access to socio-economic rights are realisable, then we need to agree that it is of paramount importance for people, who are vulnerable, poor, marginalised and/or living with HIV and AIDS, to not only access, but enjoy socio-economic rights, so as to be in the position to equally enjoy the fundamental principles of human dignity, freedom and equality. Thus, it is in the context of poverty, vulnerability, marginalisation and *'the choices that poor people do not have that the real content and meaning of socio-economic rights must be understood'* [Taylor, 2002].

However, if we are to address the limited access to socio-economic rights for especially the poor, vulnerable and marginalised members of society, we need to bear in mind, that access to socio-economic rights from a resource point of view, does not, and cannot, facilitate access to *'basic necessities of life'* in an environment free of stigma and discrimination based on one's sex, gender, sexuality and/or HIV status. As long as *'access'* is defined by both, available resources and discriminatory attitudes and practices, access will remain limited for the *'other'*, irrespective of adequate resources affording access to *'the basic necessities of life'.* Hence, only as and when both, socio-economic rights and civil and political rights are accessible and enjoyable by everyone, can an enabling environment be created in which access to *'the basic necessities of life'* is available to all, irrespective of class, race, gender, sex, sexuality and/or HIV status. Until then, the status quo remains and human dignity, freedom and equality will be denied to many…

JOHANNA KEHLER

of South Africa and others v Grootboom [13], the Court authoritatively settled the debate on the justiciability of socio-economic rights in South Africa and inquired into the reasonableness of a Provincial Housing Plan. Irene Grootboom initially lived in Wallacedene, an informal squatter settlement, in the municipal area of Oostenberg. The residents of Wallacedene lived in severe poverty, without any basic services, such as water, sewage or refuse removal. A group of about 900 people, including Irene Grootboom, began to move from Wallacedene onto adjacent, vacant, privately owned land that had been ear-marked for low-cost housing. The private landowner obtained an eviction order and the sheriff was ordered to dismantle and remove any structures remaining on the land.

The Grootboom case is an important judicial precedent, because it sets out the test for *'reasonableness'*, which will be used as a yardstick in the determination of cases similar in nature.

The evicted community had nowhere to go. Since they had lost their former sites in Wallacedene, they moved onto the Wallacedene sports field and tried to erect temporary structures. With legal assistance, the community formally notified the municipality of their situation and demanded that the municipality meet its constitutional obligation to provide temporary accommodation. Due to an unsatisfactory response from the municipality, the community – under the name of 'Irene Grootboom and 900 others' – launched an urgent application in the Cape High Court. The Grootboom community based their case on two constitutional provisions:

- Section 26 of the Constitution provides that everyone has the right to have access to adequate housing. It obliges the state to take reasonable measures, within its available resources, to make sure that this right is realised progressively.
- Section 28(1)(c) says that children have the right to shelter.

The Cape High Court rejected the first argument. It said that government's housing programme was reasonable and, thus, fulfilled the requirements of the Constitution. In terms of the second argument, the Court said that parents are primarily responsible to provide shelter for their children. If, however, they are unable to do this, Section 28(1)(c) of the Constitution places an obligation on the state to do so. Further, the Court found that the parents should be able to live with their children in the shelter, as it was not in the best interests of children to be separated from their families. Government took the decision of the High Court on appeal to the Constitutional Court. The Constitutional Court affirmed that national government bears the overall responsibility for ensuring that the state complies with its Section 26 obligations. It further found that:

- The current housing programme fell short of the state's obligation to provide relief to people in desperate need. It said that a reasonable part of the national housing budget should be devoted to providing such relief. If this was not done, the state's housing programme could not be considered reasonable for the purposes of Section 26(2).
- The state's direct obligation would apply primarily when children were removed from their families, orphaned or abandoned. [14]

The Grootboom case is an important judicial precedent, because it sets out the test for *'reasonableness'*, which will be used as a yardstick in the determination of cases similar in nature. The test of reasonableness requires the adoption of *'reasonable legislative and other measures'*. The Court stated that

> *...mere legislation is not enough. The state is obliged to act to achieve the intended result, and the legislative measures will invariably have to be supported by appropriate, well directed policies and programs implemented by the Executive. These policies and programs must be reasonable both in there implementation... An otherwise reasonable program that is not implemented reasonably will not constitute compliance with the State's obligations.* [15]

The test requires that a programme, implemented to realise a socio-economic right, must be *'comprehensive'*, *'coherent'*, *'balanced'* and *'flexible'*. The Court states further that *'a programme that excludes a significant sector of society cannot be said to be reasonable'* and that

> *Those whose rights are the most urgent and whose ability to enjoy all rights is therefore most in peril, must not be ignored by the measures aimed at achieving realisation of the right... if the measures, though statistically successful, fail to respond to the needs of those most desperate, they may not pass the test'.* [16]

The third case on socio-economic rights to come before the Constitutional Court was that of *Treatment Action Campaign v Minister of Health* [17]. The *TAC* case, as it is commonly known, dealt with the fact that government restricted the availability of Nevirapine, an anti-retroviral drug which reduces the incidence of mother-to-child transmission of HIV, to two sites in each province. This excluded a significant and vulnerable sector of society – pregnant women infected with HIV and their children, living outside the designated sites. The issue before the Court was whether or not

the women and children falling outside the designated sites had been unjustifiably excluded.

The Court directed that Nevirapine be made available at

> *...all public hospitals and clinics when, in the judgement of the attending medical practitioner, the drug is medically indicated, which shall if necessary include that the mother has been appropriately tested and counselled.* [18]

This judgement placed an obligation on the state to take reasonable measures, to extend testing and counselling facilities to the public health sector, in relation to the administration of Nevirapine. Perhaps, the most significant aspect of the TAC judgement was the stance the Constitutional Court took regarding government's argument that Courts are restricted by the separation of powers doctrine, which constrained their mandate to issuing declaratory orders only in the adjudication of socio-economic rights cases. The Constitutional Court strongly affirmed the notion that the separation of powers, as contained in the Constitution, is not absolute; *'this does not mean…that courts cannot and should not make orders that have an impact on policy'* [19].

This judgement has advanced social justice, as all pregnant women living with HIV are able to claim, as a matter of right, access to Nevirapine at any public health facility in South Africa.

Both the *Grootboom* and *TAC* cases have, through judicial enforcement, realised the socio-economic rights of a sector in society, by including them in a state led socio-economic programme.

ACCESS TO THE DISABILITY GRANT AND THE CARE DEPENDENCY GRANT FOR PEOPLE LIVING WITH HIV AND AIDS

Access to social security is a constitutionally protected right under Section 27(1)(c). The sole purpose for the state to provide social assistance to people in need is to combat poverty and, as stated by the Constitutional Court:

> *...the right of access to social security, including social assistance, for those unable to support themselves and their dependants is entrenched because as a society we value human beings and want to ensure that people are afforded their basic needs. A society must seek to ensure that the basic necessities of life are accessible to all if it is to be a society in which human dignity, freedom and equality are foundational.* [20]

The Constitutional Court strongly affirmed the notion that the separation of powers, as contained in the Constitution, is not absolute

It is submitted that in 2005, 5,2 million people were living with HIV and AIDS. There were approximately 530 000 new HIV infections and an estimated 340 000 AIDS deaths. Due to the increasing number of AIDS deaths, approximately 1,37 million children are orphaned[21]. Poverty and the HIV and AIDS pandemic coexist in a cyclic relationship. As the HIV and AIDS pandemic spirals out of control, it has a profound impact on the pockets of many individuals, families and communities. Liebenberg [2001:235] argues:

> *The poverty implications include increased health costs, a fall in productivity due to the demands on household members to care for ill members, the illness and death of breadwinners and an increase in the number of AIDS orphans. Children and working-age adults are the groups who will be most affected by the HIV/AIDS pandemic.*

People living with HIV and AIDS are entitled to access social assistance grants. However, this is subject to meeting the qualifying criteria and to passing the application of a means test. When looking at social assistance grants, one needs to be mindful of the fact that only certain categories of individuals qualify to receive social assistance grants, including children below the age of 14 years[22]; the elderly[23]; people with severe mental and physical disabilities[24]; people in extreme poverty[25]; and individuals that care for children who are vulnerable and/or orphaned[26]. It is worth noting that even within these categories, there are groups of people that cannot access social assistance grants, such as poor children above the age of 14 years; persons with chronic illnesses or moderate illnesses, including people living with HIV whose CD4 count is above 200, but who are too ill to work or carry out essential activities; child-headed households; and street children.

In the context of HIV and AIDS, the current practice of the Department of Social Development is to allocate the Disability Grant and the Care Dependency Grant to individuals with CD4 counts of below 200. The Social Assistance Act (No 13 of 2004) neither deals with this aspect nor is it regulated by the Regulation (R 813) under the Social Assistance Act of 1992. The guidelines used, or the reasoning that is adopted, in allocating these grants to people living with HIV and AIDS, with CD4 counts below 200, is still not clear.

Excluding certain groups of individuals, such as poor children above the age of 14 years, people living with HIV, with CD4 counts of more than 200, and people with chronic or moderate illnesses, from accessing any one of the grants mentioned above, raises serious questions about reasonableness. Perhaps, the answer to this question lies in the case of *Khosa v The Minister of Social Welfare and*

Population Development[27], where the Court held that

> *It is necessary to differentiate between people and groups of people in society by classification in order for the state to allocate rights, duties, immunities, privileges, benefits or even disadvantages and to provide efficient and effective delivery of social services. However, those classifications must satisfy the constitutional requirement of 'reasonableness' in Section 27(2). In this case, the state has chosen to differentiate between citizens and non-citizens. That differentiation, if it is to pass constitutional muster, must not be arbitrary or irrational nor must it manifest a naked preference. There must be a rational connection between that differentiating law and the legitimate government purpose it is designed to achieve. A differentiating law or action, which does not meet these standards, will be in violation of Section 9(1) and Section 27(2) of the Constitution.*[28]

There can be no doubt that vulnerable groups in society, such as people living with HIV and AIDS, with CD4 counts above 200, or poor children over the age of 14 years, or child-headed households, who have fallen through the gaps of the social security system, are in need of constitutional protection. This demands constitutional challenge.

CONCLUSION

While this article raised the importance of realising socio-economic rights in South Africa, it also highlighted the role and competency of the judiciary in enforcing socio-economic rights. According to Pieterse [2004:416],

> *The remains of South Africa's pre-constitutional legal culture…continues to blind South African legal scholars and judges alike to the transformative possibilities inherent in the institution of the Constitutional Court which, despite unequivocally affirming the justiciability of socio-economic rights and the judiciaries' competence to enforce them, remain peculiarly hesitant to showcase the full extent of this competence.*

The judgements of *Grootboom, TAC* and *Soobramoney* are welcomed and applauded, as they realised the rights of groups of people. However, the judicial precedents of *Grootboom* and *TAC* to achieve social justice on a wide scale have not been optimally used. There are still people living without homes, despite the victory of *Grootboom*, people are still being denied access to healthcare services, and people are still living in extreme poverty.

South Africa is celebrating the 10th Anniversary of its Constitution. Ironically, in the last 10 years only 20 cases were adjudicated on in the Constitutional Court and of those 20, only 3 were brought by the poor to access socio-economic rights. So, I ask myself where we have gone wrong. Perhaps, we need to resurrect the activists in all of us, to realise the foundational principles entrenched in our Constitution. When the foundational principles in our Constitution are undermined by our inability to act for the ones in desperate need, then faith and trust in our Constitution will turn to cynicism – and then all will be lost.

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FOOTNOTES:

1. Government of the Republic of South Africa and others v Grootboom 2001 (1) SA 46 (CC), para 22.
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3. The Constitution of South Africa, Act 108 of 1996.
4. Liebenberg, S. 2003. 'The Interpretation of Socio-Economic Rights'. In: Chaskalson, M et. al. *Constitutional Law of South Africa.* 2nd Edition, Chapter 33, p. 5.
5. Brand, D. 2005. *Socio-Economic Rights in South Africa*. Pretoria: Pretoria University Law Press. Chapter 1.
6. Page 3 of the electronic version. (www.chr.up.ac.za/centre_publications/socio/socio.html)
7. Soobramoney v Minster of Health, KwaZulu Natal 1998 (1) SA 765 (CC), para 8.
8. Liebenberg, S. 2001. 'The Right to Social Assistance: The Implications of *Grootboom* for Policy Reform in South Africa'. In *SAJHR* 17, 233.
9. Justiciability in its elementary meaning is the 'extent to which a matter is suitable for judicial determination'.
10. Government of the Republic of South Africa and others v Grootboom 2001 (1) SA 46 (CC).
11. Soobramoney v Minister of Health, KwaZulu Natal 1998 (1) SA 765 (CC).
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14. Pillay, K., Manjoo, R. & Paulus, E. Oct 2002. Budget Brief No. 111: The Grootboom Case and Women's Housing Rights. Cape Town: IDASA.
15. Government of the Republic of South Africa and others v Grootboom 2001 (1) SA 46 (CC), para 42.
16. Government of the Republic of South Africa and others v Grootboom 2001 (1) SA 46 (CC), para 42.
17. Treatment Action Campaign v Minister of Health 2002 (5) SA 721 (CC).
18. Treatment Action Campaign v Minister of Health 2002 (5) SA 721 (CC), para 135(3)(c).
19. Treatment Action Campaign v Minister of Health 2002 (5) SA 721 (CC), para 98.
20. Khosa v The Minister of Social Welfare and Population Development CCT 12/03, para 52.
21. Johnson, L. 2006. The Demographic Impact of HIV/AIDS in South Africa – National Indicators 2004. ASSA.
22. The Child Support Grant.
23. The Old Age Pension.
24. The Disability Grant for adults and the Care Dependancy Grant for children
25. The Social Relief of Distress Grant, which is only payable for a period 6 months.
26. The Foster Care Grant.
27. Khosa and others v Minister of Social Development and others 2004(6) SA 505 (CC). CCT 12/03.
28. Khosa v The Minister of Social Welfare and Population Development CCT 12/03, para. 57.

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Medical parole: Prisoners' means to access anti-retroviral treatment?

INTRODUCTION

Imprisonment must be of such a nature that only those rights that are absolutely necessary to curtail, in order to enforce the sentence of the Court, may be limited. Any limitation of rights needs to pass the test of Section 36 of the Constitution[1], which requires in Sub-section 1 the following:

> *The rights in the Bill of Rights may be limited only in terms of law of general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors, including -*
>
> *a. the nature of the right;*
> *b. the importance of the purpose of the limitation;*
> *c. the nature and extent of the limitation;*
> *d. the relation between the limitation and its purpose; and*
> *e. less restrictive means to achieve the purpose.*

The rights of prisoners and their equality, save for the limitation imposed by their imprisonment itself, have been adequately dealt with in the *ALQ* (June 2005) by Raga[2], and it is not necessary to repeat the arguments here, save to say that there is sufficient international and domestic case law to support this position.

On 6 September 2005, the Department of Correctional Services (DCS) reported to the Portfolio Committee on Correctional Services on its *'HIV/AIDS Policy for Offenders'*[3]. With regard to access to anti-retroviral treatment (ART), the DCS reported that it was not accredited to provide anti-retroviral treatment to prisoners. Two further challenges were noted, namely that the ART roll-out centres were located off site, at Department of Health facilities, and that this created security concerns as a result of staff shortages and the logistical obstacles it created, for example transport. In essence, the DCS explained that whilst it would like to provide access to ART, it lacked the resources, staff and infrastructure, to do so. The problem is, thus, primarily a practical one. Since the DCS is not accredited to provide ART in prisons, the solution must, therefore, be sought in how to bring prisoners to roll-out centres.

One possible solution, which has been proffered by some, is to utilise medical parole provisions of the Correctional Services Act (No 111 of 1998) to enable qualifying prisoners to access ART. At the briefing by the Office of the Inspecting Judge of Prisons (OIJ) to the Portfolio Committee on Correctional Services in March 2005, the OIJ pleaded for a wider and more discretionary interpretation of the medial parole conditions, as provided for in Section 79 of the Act. Reference was made in particular to prisoners who are not dying, but who require 24 hour care, special meals and assistance with basic functions, suggesting that medical parole should be considered in such cases. The OIJ did not make specific reference to ART.

This article examines the possibilities of this suggestion in an expanded manner. Is medical parole an appropriate course of action to enable prisoners who qualify for anti-retroviral therapy to access such therapy? Is this suggestion legally possible? Is this a balanced response, in terms of the rights of prisoners and society?

LEGISLATIVE AND POLICY FRAMEWORK

The legislative and policy provisions pertaining to medical care of prisoners and medical parole provisions are dealt with in the following.

Medical services

The Basic Principles for the Treatment of Prisoners provide that: *'Prisoners shall have access to the health services available in the country without discrimination on the grounds of their legal situation'*. Rule 22(1) of the UN Standard Minimum Rules for the Treatment of Prisoners (UNSMR)[5]: *'…the medical services should be organized in close relationship to the general health administration of the community or nation'*. The UNSMR further provide in Rule 22(2) that prisoners, who require specialist medical services, shall be referred to such facilities within the prison system, and if not available, to a civilian institution. The international instruments, therefore, require, as a minimum, that the principle of non-discrimination be applied and, therefore, the same quality of services available to the general population needs to be available to prisoners.

The Correctional Services Act deals with healthcare, primarily in Section 12, and requires the DCS *'…to provide, within its available resources, adequate health care services, based on the principles of primary health care, in order to allow every prisoner to lead a healthy life'*. Section 12(3) provides for access to a private medical practitioner at the expense of the prisoner. Furthermore, Section 73(2) provides for the situation, where a prisoner, whose sentence has expired, but whose release would, according to a medical officer

> *...be likely to result in his death or impairment of his or her health or to be a source of infection to other, may be temporarily detained until his or her release is authorized by the medical officer.*

The DCS *Policy on Management of HIV and AIDS for Offenders* (2005) is conspicuously silent on ART. The eleven page document only goes as far as to state that care and support will be provided, as well as that treatment will be given to prisoners infected with HIV and AIDS. The DCS *Comprehensive Programme on HIV/Aids for Offenders*[6] does, however, make reference to ART with regard to investigating the possibilities for establishing anti-retroviral therapy sites within prisons, and to further ensure compliance with the Department of Health guidelines on ART.

Parole

Chapter 7 of the Correctional Services Act deals with releases from prisons, placement on day parole, parole and correctional supervision. The provisions in the Act are detailed and somewhat complicated as a result of the different types of prison sentences that may be imposed. It is not within the scope of this article to describe these here, suffice to say that even parole boards have found the application of the provisions complex and apparently confusing.[7] Of particular relevance, however, is the provision for placement under correctional supervision, or release, on parole on medical grounds in Section 79:

> *Any person serving any sentence in a prison and who, based on the written evidence of the medical practitioner treating that person, is diagnosed as being in the final phase of any terminal disease or condition may be considered for placement under correctional supervision or on parole, by the Commissioner, Correctional Supervision and Parole Board or the court, as the case may be, to die a consolatory and dignified death.*

It is notable that unsentenced prisoners are excluded from this provision, as there is no sentence to be converted to parole, or correctional supervision. The fact that a very substantial number of prisoners spend months, if not years, awaiting trial, clearly presents a problem in this regard, especially if the person cannot be released on bail.[8] Section 62(f) of the Criminal Procedures Act (No 51 of 1977) does, however, make provisions for the accused to be placed under the supervision of a probation officer or a correctional official. Section 79 also makes a blanket provision for any sentenced prisoner to benefit from this provision; and the sentence length, offence, or type of offender, has no bearing on the decision to be made by either the Court, the Correctional Supervision and Parole Board (CSPB) or the Commissioner, on the advice of a medical practitioner. Release on medical grounds is also singular in purpose, namely to allow the prisoner to die in the comfort of his or her home, and to be assisted by his or her loved ones.

DISCUSSION

This discussion will deal with the use of medical parole, as provided for in the Correctional Services Act, for sentenced prisoners as a possible remedy to facilitate access to ART. The question is posed in response to the DCS's admitted inability, at this stage, to provide access to such treatment. Denying prisoners the opportunity to exercise the right of access to treatment is clearly a violation of domestic and international law, especially since non-incarcerated citizens have access to the treatment, in principle, under the Department of Health's *Operational Plan for Comprehensive HIV and Aids Care, Management and Treatment for South Africa* (2003). The conclusion is, thus, that, due to their legal status, prisoners are being discriminated against with regards to access to healthcare.

There is a fear that if medical parole is used... dangerous offenders, could be released and... recover significantly enough to be able to continue their criminal activities and to re-victimise society.

The need to balance the right of prisoners to adequate healthcare, on the one side, and society's expectation of punishment of offenders and need for safety, on the other side, lies at the heart of this issue. There is a fear that if medical parole is used to facilitate access to ART, dangerous offenders, suffering from AIDS related illnesses, could be released and, as a result of the therapy, recover significantly enough to be able to continue their criminal activities and to re-victimise society. If arrested, the offender would argue that keeping him or her in prison is effectively a death sentence, as it would interrupt the ART regimen. This would challenge society's expectations that offenders should be punished, and that they must serve their term of imprisonment.

The first question that needs to be answered is, whether or not the Correctional Supervision and Parole Boards (CSPBs), Courts or Commissioners are able to release a prisoner on medical parole to access ART in terms of the provisions of the Act. The powers and functions of the CSPBs, and also the purposes of parole, are described, in great detail, in the Act. There is no indication that the drafters envisaged that parole, and medical parole, could, or should be, used as a means for sentenced prisoners to access services, or resources, that the DCS is not able to provide. As noted above, the purpose of medical parole is singular, namely to allow the prisoner concerned to die a *'consolatory and dignified death*'. The purpose of medical parole is **not** to enable the prisoner to receive treatment, recover and lead a normal life. Unless the purpose of medical parole is changed, by an amendment to the Act, there does not appear to be justifiable grounds for using medical parole to access ART.

Secondly, does ART qualify as *'specialist medical services',* as described in the UNSMR (Rule 22), and if so, would it then oblige the DCS to facilitate (logistically) prisoners' access to such treatment? ART has now attained a status of general care at policy level. However,

... the DCS has a total responsibility; it is alone responsible for prisoners and cannot release prisoners, because it cannot provide adequate care.

at the level of implementation, it remains specialised treatment with a limited number of access points through the Department of Health facilities, and with one prison facility that has been accredited, bearing in mind that there are 240 prisons in South Africa. When regarded as a specialist service, ART, undoubtedly, places a duty of care on the DCS to facilitate logistically access to such specialist services. It still does not, however, enable the use of medical parole, or any other release mechanism, to access the service.

Thirdly, to release prisoners who are not dying, but require constant care, may place an undue burden on their families, who may not have the means, or training, to provide such care. In reality, a family may just resent the release, a point made by the OIJ, but for different reasons. Releasing prisoners to be placed with their families may also separate prisoners from the proper medical services, provided by the DCS, and place the prisoner in a situation that may adversely affect them, as was envisaged in Section 73(2) of the Act.

The purpose of the correctional system is, firstly, to enforce the sentences of the Courts and secondly, to detain all prisoners in safe custody, whilst ensuring their human dignity[9]. In this sense, the DCS has a **total responsibility**; it is alone responsible for prisoners and cannot release prisoners, because it cannot provide adequate care. The duty of care then remains with the DCS and it must, therefore, establish the means to provide adequate care. For example, by 2008/9 the DCS will have recruited 8000 entry level employees to enable the department to operate a seven-day week and abolish overtime. As a result of the decision to operate a seven day week system, meals are reportedly now served at times in compliance with the legislation.[10] If current capacity is lacking with regard to ART, then the DCS has a duty to develop such capacity and provide total care. It is, therefore, deeply concerning that there has only been a marginal increase in the budgetary provisions of the Medium Term Expenditure Framework (MTEF), as this indicates no plans for the required major shift in policy and expenditure.[11] From 2006/7 to 2008/9, the provision for medical services to prisoners will increase nominally by just more than 5% per annum, whilst constituting roughly 0.65% of the total budget, and shrinking.

In conclusion, parole and medical parole are not there to address the shortcomings of the prison system. If this was the case, then the DCS should have, in the first instance, released all prisoners being held in conditions that do not meet the minimum requirements specified in the Act. As the situation now stands, the state, through the DCS, has an inescapable duty to provide qualifying prisoners with access to ART in prison and in a manner that will not compromise their health any further.

FOOTNOTES:

1. The Constitution of South Africa, Act 108 of 1996.
2. Raga, U. 2005. 'Prisoners have rights too…'. In *ALQ*, June 2005, pp. 20-21.
3. PMG Minutes of the Portfolio Committee on Correctional Services, 6 September 2005. The minutes included a copy of a presentation on the topic distributed by the DCS representatives.
4. PMG Minutes of the Portfolio Committee on Correctional Services, 15 March 2005.
5. Standard Minimum Rules for the Treatment of Prisoners, Adopted by the First United Nations Congress on the Prevention of Crime and the Treatment of Offenders, held at Geneva in 1955, and approved by the Economic and Social Council by its resolutions 663 C (XXIV) of 31 July 1957 and 2076 (LXII) of 13 May 1977.
6. The document is undated and was received from DCS as a policy document in 2006. Copy on file with author.
7. For a more detailed description of problems experienced in one particular case (Motsemme H v Min of Correctional Services), see CSPRI Newsletter No. 14, (http://www.easimail.co.za/BackIssues/cspri/0912_Issue639.html)
8. At the end of August 2005, there were nearly 21 000 awaiting trial prisoners who had been in custody for longer than three months. Of this group, 1528 had been in custody for longer than two years. (Information supplied by the Office if the Inspecting Judge)
9. Correctional Services Act, Section 2(a and b)
10. Correctional Services Act, Section 8(5)
11. Estimates of National Expenditure, 2006/7, Vote 20 – Correctional Services, p. 449.

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Shawn Hattingh

Socio-Economic Rights versus Civil and Political Rights

The South African Constitution[1], through the Bill of Rights, enshrines fundamental rights and freedoms to which everyone is equally entitled and has the right to equally enjoy.

These rights include both socio-economic rights – such as the right to access housing, healthcare, food, water, social security and education – and civil and political rights – such as the right to equality and non-discrimination, to human dignity, to life, to security, to freedom of expression, and to privacy. The philosophical aim of guaranteeing these rights is, arguably, to ensure that the historical levels of inequality, both in political and material terms, are alleviated and that the lives of all people, including people living with HIV and AIDS, are improved.

It is within that context, that this article explores the correlation between civil and political rights and socio-economic rights, and raises the question whether or not people's civil and political rights, including the right to equality, can be fully enjoyed if their access to socio-economic rights is limited. In order to do this, the article examines the differences between socio-economic rights and civil and political rights in the context of the South African Constitution. In addition, it explores the extent to which people are in the position to access socio-economic rights, and how this, in turn, impacts on the extent to which the right to dignity, the right to equality, and the right to life can be realised.

CIVIL AND POLITICAL RIGHTS AND SOCIO-ECONOMIC RIGHTS WITHIN THE SOUTH AFRICAN CONSTITUTION

Most constitutions, throughout the world, tend to only define civil and political rights, and not socio-economic rights, as fundamental human rights.[2] This is largely justified by the belief that civil and political rights are self-executing, that they can be immediately realised, and that their fulfilment does not place a significant material burden on the state. Part of this justification, conversely, also includes the notion that socio-economic rights cannot be realised immediately, because of the costs involved for the state. As a result, most states explicitly hold the view that socio-economic issues and rights, at best, belong in the realm of politics and not within legal systems[3]. In such a view, socio-economic rights are defined as being subordinate to, and of less importance than, civil and political rights. Most states, therefore, do not wish or believe that it is necessary to define socio-economic rights as fundamental human rights[2] within their constitutions.

The South African Constitution, however, takes a different approach, in that it enshrines both civil and political rights and socio-economic rights as fundamental human rights. For this reason, the South African Constitution has been hailed as one of the most progressive constitutions in the world. The Constitution also takes the progressive step of stipulating that socio-economic rights, like civil and political rights, are subject to judicial enforcement. Thus, if these rights are violated, the Courts can be approached for relief.[4] Nonetheless, the South African Constitution still makes certain distinctions between civil and political rights and socio-economic rights, which have far reaching practical implications for all people living within South Africa.

The Constitution stipulates that civil and political rights, such as the right to equality and non-discrimination (Section 9); the right to human dignity (Section 10); the right to life (Section 11); the right to freedom and security of the person (Section 12); the right to freedom from forced labour (Section 13); the right to privacy (Section 14); the right to freedom of religion, belief and opinion (Section 15); the right to freedom of expression (Section 16); the right to freedom of association (Section 18); the right to vote (Section 19); the right to citizenship (Section 20); the right to freedom of movement (Section 21); the right to freedom of trade,

occupation and profession (Section 22); the right to fair labour practices (Section 23); and the right to access the courts (Section 34), are rights, which should be immediately respected, protected, promoted and fulfilled by the state.

However, under certain extreme conditions, such as in a time of war, some of these civil and political rights can be limited. Nonetheless, some rights, including the right to equality and non-discrimination; the right to human dignity; the right to life and the right to freedom of security of the person are viewed as non-derogable rights in the Constitution, which means that they cannot, under any circumstances, be limited. This, arguably, indicates that the Constitution places a strong emphasis on the need for the state to immediately recognise and respect people's civil and political rights, especially the rights that are defined as non-derogable.

...the Constitution only places an obligation on the state to ensure people have access to, and not full enjoyment of, socio-economic rights. This access ... does not, in fact, have to be free access either.

On the contrary, the Constitution specifies that the majority of socio-economic rights, such as the right to access housing, land, healthcare, sufficient food, water, and social security, do not have to be immediately fulfilled by the state . In fact, the Constitution states that the government only has to undertake progressive steps, within the limit of its available resources, towards ensuring that people have access to socio-economic rights. These progressive steps can include producing relevant legislation, policy documents and/or allocating resources towards addressing issues around the access to socio-economic rights.

Nevertheless, it is important to bear in mind that the Constitution only places an obligation on the state to ensure people have **access to**, and not full enjoyment of, socio-economic rights. This access to socio-economic rights does not, in fact, have to be free access either. Hence, even though the Constitution does not explicitly make a distinction in importance between socio-economic and civil and political rights, it does, however, do so by defining civil and political rights as immediate and socio-economic rights as non-immediate. This translates into a situation where, in many cases, government can remain within the constitutional boundaries, even though they may not be directly addressing people's socio-economic needs – all government has to do is to demonstrate that they are working towards addressing these needs. This means that government can still, for example, justify not providing adequate healthcare to all people, as long as they can demonstrate that they have formulated progressive plans, and are taking some steps – even if they are fairly limited – to do so in the future. Indeed, these plans do not necessarily have to include timeframes, only a *'commitment'* that access to adequate healthcare would be provided to all people at some, undefined, point in the future.

THE REALITY OF SOCIO-ECONOMIC RIGHTS

It is common knowledge that inequality, in terms of income and access to resources, appears to be ever-growing in South Africa.

...government can still, for example, justify not providing adequate healthcare to all people, as long as they ... are taking some steps – even if they are fairly limited – to do so in the future.

According to the United Nations Human Development Index[8], 48.5% of South Africans live below the poverty line[9], while more than 40%[10] of the working age population is unemployed. In real terms, income inequality increased between different sections of the population from 1993 to 2004.[11] This growing inequality also means that accessing and

realising socio-economic rights remains, for many people, but a dream.

The South African Human Rights Commission[12] notes that many people have no access to adequate housing, clean drinking water, elementary social services, sufficient nutrition, and adequate healthcare services. In reality, many people are denied access to social grants, due to a lack of documentation, maladministration and the poor standards at the service delivery points; many people are denied access to water, because of the cost-recovery system and inadequate infrastructure; many people are denied adequate healthcare, because of staff shortages, a lack of resources at public hospitals and clinics and/or due to their HIV status; and many people are also denied access to prevention, such as condoms, because of their age – to name but a few examples of persistent limited access to socio-economic rights. In fact, due to growing inequality and limited access to socio-economic rights, combined with the growing HIV and AIDS pandemic, life expectancy in South Africa dropped from 56 years old in 1996 to 48 years old in 2003.[13]

...plans do not necessarily have to include timeframes, only a *'commitment'* that access ...would be provided at some, undefined, point in the future.

Hence, the constitutional provisions, regarding access to socio-economic rights, seemingly mean very little, if they are not integrated into people's lives. In fact, the lack of access to socio-economic rights, such as the right to sufficient food, water, and healthcare, is undermining people's civil and political rights, such as the right to human dignity, the right to equality, and even the right to life. Indeed, a lack of access to socio-economic rights for people living with, and affected by, HIV and AIDS can have catastrophic consequences, both in terms of their health and their living conditions.

Many households have experienced a loss of, or reduction in, income, because of the effects of HIV and AIDS. Without a broad social security safety net and a free quality public healthcare system, the responsibility for caring for ill household members often falls on the remaining healthy household members, which, in turn, undermines the possibility of them maintaining, or finding, employment. As a result, many households not only lose the income of ill household members, but also that of healthy household members. This all leads to greater poverty within these households and further undermines their scope to fully access socio-economic rights.

The cost of healthcare and treatment also places a further burden on these households. Households affected by HIV and AIDS are often forced to divert scarce resources, which would have been allocated to accessing food, water, transport, and housing, to cover the growing medical costs that are associated with HIV and AIDS. This often, and very directly, negatively impacts on the extent to which socio-economic rights, such as the right to access sufficient food, water and adequate housing, can be realised by various members of the household, which in turn undermines the right to dignity and, in some cases, the right to life for members of the household. Indeed, if a household lacks not only income, but also access to free quality healthcare, the medical costs, associated with the treatment and care of HIV, can become totally pro-hibitive, resulting in a situation, in which civil and political rights, such as the right to dignity, are equally limited for both, the infected and affected member/s of the household.

The reality is that the lack of access to socio-economic rights has a spiral effect in that it contributes to growing inequality within our society, which in turn affects people's *'ability'* to access socio-economic rights. The full enjoyment of civil and political rights is, therefore, contingent on the full realisation of socio-economic rights.

... if socio-economic rights are not met now, the consequences are that generational poverty and inequality will continue.

CONCLUSION

Adequate access to socio-economic rights is not only crucial for people's physical survival, but is also crucial for people's quality of life and development. A lack of access to socio-economic rights not only undermines a person's present civil and political rights, it also, to a large degree, undermines their future prospects. In other words, if socio-economic rights are not met now, the consequences are that generational poverty and inequality will continue. Indeed, if we are to have a society that truly values human rights, then that society should gather all its material, economic, social and political resources to address the conditions that perpetuate poverty and the marginalisation of large sectors of the population.

The argument that the full enjoyment of civil and political rights depends on the realisation of socio-economic rights, does, however, not mean that socio-economic rights are more important than civil and political rights. In reality, it means that one cannot differentiate in importance between civil and political rights and socio-economic rights. Both are equally important, both are inter-related, and both are inseparable.

... 48.5% of South Africans live below the poverty line, while more than 40% of the working age population is unemployed...

Violations of people's civil and political rights, such as the right to equality and non-discrimination, can also undermine their position to access socio-economic rights. For example, stigma and discrimination, based on gender, sex, sexual orientation and/or HIV status, often leads to people being denied access to socio-economic rights by service providers, including the right to access healthcare. In reality, many people living with HIV continue to be denied access to credit facilities, which directly undermines the possibility of accessing the right to adequate housing, due to prevailing stigma and discrimination. Hence, access to socio-economic rights will remain limited and become meaningless, as long as violations against people's civil and political rights, based on their sex, gender, sexual orientation and/or HIV status, continues.

...life expectancy in South Africa dropped from 56 years old in 1996 to 48 years old in 2003.

Hence, true equality cannot be achieved without the full recognition, the full realisation and the full enjoyment of civil, political and socio-economic rights. Indeed, civil, political and socio-economic rights are truly fundamental human rights.

FOOTNOTES:

1. The Constitution of South Africa, Act 108 of 1996.
2. Devenish, G. 1998. *A Commentary on the South African Constitution*. Durban: Butterworth.
3. Seleoane, M. 2001. *Socio-Economic Rights in the South African Constitution: Theory and Practice.* Cape Town: HSRC Press.
4. Heyns, C. 1998. 'Advancing Social Justice in South Africa through Economic and Social Rights: From the margins to the mainstream.' In *ESR Review*, Vol. 1, No. 1.
5. Section 37 of the Constitution.
6. The only socio-economic rights that have to be implemented without delay are children's socio-economic rights, the right to basic education, and the right not to be subjected to arbitrary evictions.
7. Section 26 (2), Section 27(2) of the Constitution. See also Liebenberg, S. & Pillay, K. 2000. *Socio-Economic Rights in South Africa*. Cape Town: Community Law Centre.
8. UNDP. 2003. South Africa: Human Development Report.
9. Absolute poverty line in South Africa is calculated as R 354 per month per adult.
10. Statistics South Africa. 2004. Labour Force Survey. Expanded definition of unemployment.
11. Van der Berg, S. et al. 2005. Trends in poverty and inequality since political transition. (http://www.eldis.org)
12. South African Human Rights Commission. Economic and Social Rights Report 2002/2003. Pretoria: SAHRC.
13. United Nations. 2005. Human Development Report.

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Fritz Gaerdes

Refugees and Disability Grants: Should the most vulnerable be excluded?

Overview

Refugees are persons who have fled their countries of origin due to individual persecution, or conditions of war, or events seriously disrupting public order.[1] Most refugees in South Africa appear to have fled conflict situations on the African continent.[2]

Disabled refugees are extremely vulnerable members of any society, both as refugees and as persons with disabilities. Refugees do not receive social assistance from the South African state. In their current forms, the legislative schemes that regulate social assistance in South Africa totally exclude disabled refugees from gaining access to appropriate social assistance. However, Section 27(f) of the Refugees Act (No 130 of 1998) does allow recognised refugees to seek employment in South Africa. It, thus, seems to be the South African government's policy that refugees should provide for their and their families' socio-economic needs themselves, through employment.

Many disabled refugees cannot work because of their disability. This exacerbates their vulnerability, as they are seldom able to sufficiently maintain themselves or their families. Their vulnerability is exacerbated by the fact that most refugees do not have extensive networks of family or friends in South Africa, to whom they can turn when they become economically incapacitated, due to a disability.

For reasons intrinsic to their status as refugees, they usually also cannot turn to the diplomatic representatives of their governments in South Africa, or even return to their countries of origin to seek social assistance. Neither can they currently turn to the South African government for such assistance when they become disabled.

South Africa's failure to provide this vulnerable group with access to appropriate social assistance may unjustifiably limit some of their constitutional rights.

This statement must be evaluated with reference to the relevant statutory provisions providing for social assistance grants, how these provisions exclude refugees and whether or not these statutory provisions are on face value in line with the provisions of the South African Constitution and international law.

The current legislative scheme: The Social Assistance Act (No 59 of 1992)

Section 27 of the Constitution[3] mandates appropriate social assistance for persons, who are unable to maintain themselves. The legislative schemes contained in the current, and new, Social Assistance Acts constitute part of the state's commitment to making available appropriate social assistance to disabled persons, by providing grants.

The current Social Assistance Act and its Regulations is the prevailing law that regulates the provisions of social assistance. Section 3 of the current Social Assistance Act sets the requirements to qualify for a disability grant. It provides that any disabled person shall be entitled to the appropriate social grant, if the person satisfies the Director General that she or he is a disabled person, is resident in the Republic at the time of the application in question, is a South Africa citizen or a permanent resident of the Republic, and complies with the prescribed conditions.

In addition to these requirements, Regulation 9 requires a copy of the applicant's identity document to accompany an application for a disability grant. Regulation 1 defines an identity card to mean an identity card referred to in Section 14 of the Identification Act (No 68 of 1997).

In terms of Section 3 of the Identification Act, that Act shall apply only to persons who are South African citizens or permanent residents. The Identification Act, therefore, does not apply to refugees. Accordingly, refugees are not issued with identity cards in terms of the Identification Act. Instead, refugees are issued with refugee identity documents, in terms of Sections 27 and 30 of the Refugees Act. Refugee identity documents do not satisfy the definition of '*an identity card'* within the terms of the Social Assistance Act.

Both the requirement that a person must be a South African citizen or permanent resident of South Africa, and the requirement that an applicant for a grant must submit a copy of her or his identity card, issued in terms of the Identification Act, present total legal exclusions to refugees from enjoying access to social assistance.

The new legislative scheme: The Welfare Laws Amendment Act and the Social Assistance Act (No 13 of 2004)

Recently, a number of amendments have been proposed to the current legislative scheme regulating social assistance. Unfortunately, they will not bring relief to disabled refugees, if implemented.

During 1997, the President of South Africa assented to the Welfare Laws Amendment Act (No 106 of 1997). If enacted, this Amendment Act will replace almost the entire current Social Assistance Act. To date, it has only been brought into force in respect of the Child Support Grant.

In respect of the Disability Grant, the current Social Assistance Act accordingly remains the prevailing law. Should the Welfare Laws Amendment Act be brought into force, applicants for Disability Grants will still have to be a South African citizen or permanent resident to qualify. This amendment will, thus, not provide relief for disabled refugees.

In another legal development, the President, during 2004, assented to the Social Assistance Act (No 13 of 2004) (hereinafter 'the new Social Assistance Act'). To date, the new Social Assistance Act has not come into force. When it does, it will repeal the current Social Assistance Act and its Regulations. However, Section 5 of the new Social Assistance Act also requires an applicant to be a South African citizen, which means it will not bring relief to disabled refugees, when coming into force.

Refugee identity documents do not satisfy the definition of *'an identity card'* within the terms of the Social Assistance Act.

In one of the most recent legislative developments, the Minister of Social Development, during February 2005, published Draft Regulations for public comment. In these Draft Regulations it is proposed that an applicant must have a valid identity document to apply for a Disability Grant. Similar to the provisions of the current Social Assistance Act, Draft Regulation 1 defines an identity document to mean an identity document referred to in Section 14 of the Identification Act.

It is clear that should these Draft Regulations be made into the Regulations supporting the new Social Assistance Act, when it comes into force, disabled refugees will still not have access to the Disability Grant, because they do not have access to identity cards, issued in terms of the Identification Act.

Relevant statutory, constitutional and international law

As shown, the current, and future envisaged, legislative schemes totally exclude disabled refugees from having access to appropriate social assistance in the form of Disability Grants.

Such exclusion limits the rights of disabled refugees to enjoy equality, dignity and social assistance in South Africa. It is a limitation that seems not to be justifiable in terms of either the provisions of the Constitution, domestic refugee law or international law. The reason for this view will be briefly explained with reference to relevant legal provisions.

The Constitution and the Refugees Act provides for the rights and obligations of refugees resident in South Africa. The Refugees Act came into force on 1 April 2000. Section 27(b) specifically provides that refugees should enjoy full legal protection in South Africa, which must include the rights set out in Chapter 2 of the Constitution.

Chapter 2 of the Constitution contains the Bill of Rights. Section 27(1) thereof provides that everyone has the right to have access to social security, including if they are unable to support themselves and their dependants, appropriate social assistance.

Section 9 entrenches the right to equality for everyone. The state may not unfairly discriminate, directly or indirectly, against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.

Section 10 of the Constitution guarantees that everyone has inherent dignity and the right to have their dignity respected and protected, whilst section 7(2) imposes a duty on the state to respect, protect, promote and fulfil the rights in the Bill of Rights.

The legislative schemes described above are in breach of the various rights in the Bill of Rights and, as such, the state is in breach of Section 7(2) of the Constitution.

It is an established principle of South African law that the word *everyone*, when interpreting sections 9, 10 and 27 of the Constitution, also include non-citizens.[4] I submit that this term should also embrace refugees within the context of Constitutional interpretation.

It is not only domestic law that seems to obligate the government to provide disabled refugees with equal access to the social assistance, to which disabled South African citizens presently have access, international law also appears to demand this.

The Refugees Act must be interpreted with due regard to the provisions of the 1951 UN Convention Relating to the Status of Refugees, and the 1967 Protocol thereto, and any other relevant convention or international agreement, to which South Africa has become a party.[5]

South Africa has unreservedly ratified the UN Refugee Convention and the African Charter on Human and Peoples' Rights, 1986. By ratifying the African Charter, South Africa legally committed itself to ensure that every person within South Africa's borders should enjoy equality and dignity, and that all disabled persons lawfully within South Africa should enjoy special measures of protection, in keeping with their physical and moral needs.[6]

South Africa, in terms of Article 24 of the UN Refugee Convention, undertook to accord refugees, lawfully staying in its territory, the same treatment that it accords to its citizens, in respect of access to social assistance, such as disability grants.

It is, thus, an anomaly that whilst the South African government voluntarily accepted these legal obligations, it has not, to date, incorporated them into the legislative framework regulating social assistance.

Justification for the limitation of the rights of refugees

The lack of financial resources may well be offered as justification for the limitation of refugees' rights in the context of social assistance. However, a brief analysis of the social profile of refugees, and the numbers involved, illustrates that the additional resources required to uphold the rights of disabled refugees, is limited, and may not actually sustain this justification for limitation of their rights.

Although there is no precise figure of the number of recognised refugees in South Africa, it is estimated that the Department of Home Affairs has formally recognised approximately 28 000 persons as refugees since 1994.[7] Refugees appear to be an extremely small group of persons.

Refugee status, like citizenship, is a personal attribute that is very difficult to change, one which has not been made by choice and over which an individual has very little control.

In addition to persons formally recognised, there are approximately between 85 000 and 115 000 persons, who still await the outcome of their applications for asylum.[8] It is not clear what the number will be exactly, but one can assume that the number of formally recognised refugees may increase to some extent, when this backlog is addressed.

However, the number of disabled refugees, as with any population group would never, in absolute terms, amount to a significant proportion of the refugee population in South Africa as a whole.

Due to the small number of refugees in South Africa, it is government policy that refugees integrate with the society. Refugees here, unlike the situation in many other African countries, are not housed in refugee camps. In countries where such camps exist, these camps constitute the welfare arrangements for the refugees.

Because the number of refugees in South Africa is relatively small, it is probable that the policy of local integration will continue. It is, therefore, unlikely that the South African government will, at any stage, have to make special welfare arrangements for large numbers of refugees. In any event, if South Africa is faced by a large-scale influx of refugees, the government is not precluded from assessing the welfare arrangements to be made for refugees at that stage.

At present, the Disability Grant is R780 per month. In terms of the total budget for expenditure on social grants, which amounts to tens of billions of Rands every year, the expenditure to provide grants for disabled refugees would be negligible.

Whatever the exact amount, the additional financial expenses in respect of social assistance for disabled refugees would most likely never amount to any significant increase in the overall budget. Financial constraints of this relatively small magnitude should not be allowed to defeat the Constitutional claims of refugees. This is particularly so, if regard is given to the expenditure by the state on a wide range of relatively unimportant matters.[9]

Conclusion

Refugee status, like citizenship, is a personal attribute that is very difficult to change, one which has not been made by choice and over which an individual has very little control. Refugees are denied access to the Disability Grant, solely because of their refugee status. In South Africa, refugees are a marginalised minority group, with no political power or rights whatsoever. They cannot, therefore, change their exclusion from accessing appropriate social assistance through political means.

Viewed against South Africa's constitutional provisions, and the international legal obligations that this country has undertaken, such exclusion may not only be morally unacceptable, but may perhaps be legally challengeable.[10]

FOOTNOTES:

1. Section 3(a) of the Refugees Act (No 130 of 1998) provides that a person qualifies for refugee status if he or she has: *'A well-founded fear of being persecuted by reason of his or her race, tribe, religion, nationality, political opinion or membership of a particular social group, is outside the country of his nationality and being unable or unwilling to avail himself of the protection of that country…'* whilst Section 3(b) provides that a person qualifies for refugee status if *'Owing to external aggression, occupation, foreign domination or events seriously disturbing or disrupting public order in either part or the whole of his or her country of origin or nationality, is compelled to leave his or her place of habitual residence in order to seek refugee elsewhere'.*
2. See generally UNCHR. 2005. *Discussion document on measures to clear the backlog in asylum applications*. February 2005.
3. The Constitution of South Africa, Act 108 of 1996.
4. See generally: Larbi-Odam v. MEC for Education (North West Province) 1998 (1) SA 745 (CC), Khosa and others v. Minister of Social Development and others 2004(6) SA 505(CC) at Para 47, Lawyers for Human Rights and another v. Minister of Home Affairs and others 2004(4) SA125 (CC) at Para 26.
5. Section 6 of the Refugees Act.
6. See Articles 3, 5 and 18(4) of the African Charter on Human and People's Rights.
7. See generally UNCHR. 2005. *Discussion document on measures to clear the backlog in asylum applications.* February 2005. Para 3.
8. Ibid at Para 4.
9. But one example of this is the recent widely publicised state expenditure of hundreds of thousands of Rands on air transport for the private travel arrangements of senior state functionaries.
10. On 19 September 2005 an application challenging the Constitutionality of the exclusion of disabled refugees from accessing appropriate social assistance was launched in the Pretoria High Court under case no. 32054/ 2005. Recently, an interim settlement agreement was concluded between the litigating parties, wherein the South African government, amongst other things, have agreed to file a written *'Social Assistance Plan for Refugees'* by 31 March 2006, in which they will set out the exact manner in which they intend to give effect to their legal obligations towards disabled refugees.

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Bryge Wachipa

Realising the right of access to healthcare for poor people living with HIV and AIDS

Whenever we lift one soul from a life of poverty, we are defending human rights. And whenever we fail in this mission, we are failing human rights.
(Kofi Annan)[1]

INTRODUCTION

It is estimated, that 71% of all the people who are infected with HIV in the world live in sub-Saharan Africa, while this region contains only 11% of the world's population. South Africa is the country with the largest population living with HIV and AIDS.[2]

In South Africa, the increase in prevalence of HIV incidences over a 14 year period, arguably demonstrates the failure of prevention strategies, underpinned by a lack of political will. A study by the Human Science Research Council (2005)[3] indicates that in 2005, between 4.8 and 5.3 million South Africans, aged 2 years and older, were living with HIV and AIDS. A further research of the national probability sample of South African educators revealed that 22%, of the ones infected with HIV, had CD4 cell counts below 200.[4] The impact of HIV and AIDS falls disproportionately on the poor population of the country, placing major challenges on the enhancement and acceleration of the overall poverty eradication efforts, meant to avoid the continued downward slide and marginalisation of a significant portion of society.[5]

The government is providing ARV therapy through the public healthcare system. Although, not everyone living with the virus is in need of treatment, it remains a matter of concern that only about 45 000 people are on anti-retroviral treatment (ART), through the public health facilities, in a country where more than 200 000 people are in dire need of treatment.[6] HIV and AIDS has an adverse impact on many parts of the society, including demographic, household, health sector, educational, workplaces and economic aspects. Furthermore, the pandemic has brought protracted illness, premature death and grief to millions of people.[7]

THE CONSTITUTIONAL PROVISIONS

Chaskalson (1998) describes South Africa's past as scarred by *'disparities of wealth and skills between those who benefited from colonial rule and apartheid and those who did not.'*[8] Now, South Africa celebrates a *'progressive national constitution'*, that guarantees socio-economic rights, including the right of access to healthcare, not as directive principles of state policy, but as fully fledged rights, incorporated in the Bill of Rights, on the same footing as the civil and political rights.[9]

Although, the inclusion of socio-economic rights in the Constitution was supported by various political organisations, their inclusion did not go unchallenged. Various objections were raised in the process of the certification of the 1993 Interim Constitution of South Africa, including that civil and political rights are self-executing, while socio-economic rights are not; that the implementation of socio-economic rights is a subject matter of politics, and not of law; that the judicial review is an infringement on the separation of powers doctrine; that socio-economic rights raise budgetary issues; and that socio-economic rights are programmatic in nature, and, therefore, not capable of immediate realisation. These arguments were subsequently rejected by the Constitutional Court.[10]

STATE OBLIGATIONS

In the Preamble of the Constitution[11], one of the aims stated is to *'improve the quality of life of all citizens and free the potential of each person'*. The Constitution, in Section 7(2), imposes three levels of obligations on the state, namely the duty (i) to respect, (ii) to protect, and (iii) to promote and fulfil the rights in the Bill of Rights. The duty to respect is regarded as a negative duty, while the duties to protect, promote and fulfil impose a positive obligation on the State. It is argued, that in developing an understanding of the nature of the obligations imposed by socio-economic rights, it will be possible to identify as and when the rights are being violated.[12]

Positive duties entail that the state must take positive measures

towards the realisation of the right. The state, for example, may enact legislation, policy or allocate resources. Negative duties entail that the state deters from infringing upon the enjoyment of the right. Despite the apparent clarity, the distinction between positive and negative duties, goes, in reality, beyond the literal distinction between acting and not acting. In South Africa, the Courts employ a more robust scrutiny in cases of negative breach. The Courts find such cases to be less intrusive to the separation of powers.[13] However, often, the same conduct can result in a breach of the positive duty to fulfil and negative duty to respect and, thus, making it difficult to use the distinction.[14]

THE RIGHT TO ACCESS HEALTHCARE

There are various constitutionally guaranteed rights aimed at the protection of health as a right, including the right to bodily and psychological integrity, which encompasses the right to reproductive choices, the right to security in and control over one's body, and the right not to be subjected to medical or scientific experiments without one's informed consent (Section 12(2)); the right to an environment that is not harmful to one's health or well-being (Section 24(a)); children's right to basic nutrition, shelter, basic healthcare services and social services (Section 28(1)(c)); and the right of detainees and sentenced prisoners to conditions of detention that are consistent with human dignity, including the provision of adequate accommodation, nutrition, reading material and medical treatment (Section 35(2)(e)). Other rights enshrined in the Constitution, which support the full realisation of the health rights, include the right to equality (Section 9), right to human dignity (Section 10), the right to life (Section 11), the right to privacy (Section 14), the right to education (Section 29), the right to adequate housing (Section 26), and the right to sufficient food and water (Section 27).

Positive duties entail that the state must take positive measures towards the realisation of the right.

However, central to this discussion is Section 27 of the Constitution, stating that:

> *(1) Everyone has the right to have access to –*
> *(a) health care services, including reproductive health care;*
> *(b) sufficient food and water; and*
> *(c) social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.*
> *(2) The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.*
> *(3) No one may be refused emergency medical treatment.*

Section 27 guarantees everyone the right of access to healthcare services and emergency medical treatment, and obliges the state to take reasonable measures to achieve the realisation of these rights.[15] For the Constitution to become relevant in the fight against HIV and AIDS, and in the protection of people infected and affected by HIV and AIDS, one must clearly understand the obligations it creates.

However, *'healthcare services'* are not defined in the Constitution. It has been suggested that these services must include proper medical care, prevention and diagnosis of diseases and vaccination. This suggestion still does not elucidate the content of the right. In other words, the difficulty is that it is often not clear to what extent the State has to guarantee access to healthcare.[17] For example, it is not clear what constitutes *'emergency medical treatment'*, because it may be argued that most medical conditions are emergencies, as viewed from the patient's perspective.

JUSTICIABILITY OF SOCIO-ECONOMIC RIGHTS IN THE CONSTITUTION

The Constitutional Court is constitutionally mandated to interpret and give effect to the rights in the Bill of Rights.[18] Liebenberg [2004:7] describes the Court's role as that of achieving

Negative duties entail that the state deters from infringing upon the enjoyment of the right.

> *...a critical balance between effectively protecting the socio-economic rights of the poor, while also respecting the roles of the legislature and executive as the primary branches of government responsible for realising socio-economic rights.*

Although, there are various challenges in constitutional litigation, the Constitutional Court has clearly expressed itself on the

For the Constitution to become relevant in the fight against HIV and AIDS, ... one must clearly understand the obligations it creates.

justiciability of socio-economic rights. The Court views socio-economic rights as justiciable human rights. In the case *In re: Certification of the Constitution of the Republic of South Africa*[19], the Court held that the socio-economic rights *'are, at least to some extent justiciable; and [at] the very minimum…can be negatively protected from invasion.'* In doing so, the Court takes due regard of various factors including the historical context.[20] The total of these factors allows for judicial intervention, where government programmes, designed to meet the socio-economic needs over a medium or long-term period, exclude the immediate measure of relief for people in desperate need of government assistance.[21] The *TAC* case, like other cases on socio-economic rights, has resulted in policy formulation by the government, targeting strategic framework of intervention including treatment, care, prevention and support.

IMPLICATIONS OF THE COURT'S JURISPRUDENCE

In *Treatment Action Campaign v Minister of Health*[22], the applicants contended that the government acted against its own policy, which entitled pregnant women and children under the age of 6 years to free health services.[23] The applicants also suggested that the selection of the pilot sites available was discriminatory against the poor, which were indirectly discriminated against on the grounds of race.[24] Thirdly, they contended that the government's approach encroached on the basic fundamental rights of access to healthcare (Section 27), basic health services for children (Section 28(1)(c)), the right to life (Section 11), the right to human dignity (Section 10), the right to equality (Section 9), and the right to make reproductive choices (Section 12(2)(a)). The applicants also argued that the state was in breach of its negative duty and, thus, attempted to get the Court to endorse a *'minimum core'* approach.

The Reasonableness Approach

As the Court rejected the *'minimum core'* approach, it adopted a *'reasonableness test'*. A detailed account of the reasonableness test, used to assess the State's compliance with the obligation to realise socio-economic rights, is set out in the Constitutional Court case of *Government of the Republic of South Africa v Grootboom*[25]. The approach has been described as a *'means-end'*, and requires that the measures be evaluated to determine whether or not they are *'capable of facilitating the realisation of the right'*. The following principles were established:

- The programme must be comprehensive, coordinated, clearly allocate responsibilities and tasks to the different spheres of government, and ensure that *'the appropriate financial and human resources are available'*.[27]
- Although, each sphere of government is responsible for implementing parts of the programme, national government has the overarching responsibility to ensure that the programme adequately meets the State's constitutional obligations.[28]
- The programme *'must be capable of facilitating the realisation of the right'*[29]
- Policies and programmes must be reasonable, *'both in their conception and their implementation'*.[30]
- The programme must be *'balanced and flexible and make appropriate provision for attention to housing crises and to short-, medium-and long-term needs'*. A reasonable programme cannot exclude *'a significant segment of society'*.[31]
- The programme must include a component that responds to the urgent needs of people in desperate situations. Thus, a reasonable programme, even though, it is statistically successful in improving access to housing, cannot *'leave out of account the degree and extent of the denial of the right they endeavour to realise'*.[32]

The question of *'available resources'* is hard to grasp. It demands that one distinguishes between lack of will and inability to realise the right.

The poor are particularly vulnerable and their needs require special attention. It is not certain whether or not these principles can effectively assist the poor. The precise parameters of this test are still under debate.[33]

Available Resources

The question of *'available resources'* is hard to grasp. It demands

that one distinguishes between lack of will and inability to realise the right.[34] Clearly, socio-economic rights in the Constitution do not require the state to do more than is achievable within its available resources. Availability has been described by the Committee on ESCR.[35] The healthcare sector is but one of the many sectors, such as education and social welfare, that are competing for scarce resources against the backdrop of historical neglect. Nevertheless, healthcare facilities, goods and services have to be available in sufficient quantity; must be physically and economically accessible (affordable) to everyone; must be ethically and culturally acceptable; and must be of a medically appropriate quality. Consequently, the amount of resources required will feature prominently in any adjudication of the constitutionality of government's programme for increasing access to ARV treatments.[36]

Progressive Realisation

The State is not expected to ensure the full realisation of the right immediately. The Constitution requires the right of access to healthcare to be realised *'progressively'*, through *'reasonable'* legislative and other measures. This duty is based on the notion that individuals will provide for themselves. However, the state has a duty to help individuals to access the right, and where they are unable to do so, to provide direct assistance or services.

As Brand [2005:2] argues,

> *...constitutional socio-economic rights are blueprints for the state's manifold activities that proactively guide and shape legislative action, policy formulation and executive and administrative decision-making.*

The Court must examine *'legal, administrative, operational and financial hurdles and, where possible, lower these barriers over time'*.[37] In the context of HIV and AIDS, this requirement does not only imply a gradual increase of numbers of people accessing ARV treatment, but also includes improved quality of care and medicines.

KEY CHALLENGES

There are a number of challenges flowing from the South African experience in applying the socio-economic rights in the Constitution.

- The importance of socio-economic rights in the Constitution will diminish, if the Courts interpret them as imposing weak obligations on government. There is no precise definition of the scope and content of the right of access to healthcare. The Constitutional provisions do not show the state obligations (the minimum core) from which partial fulfilment should result in judicial intervention.
- The HIV crisis requires a multi-faceted approach. It demands a human rights-based approach to prevention, treatment, care and support programmes. There is, therefore, a need for a systematic and coordinated approach to effectively reduce the spread, and impact, of HIV and AIDS, as well as to reduce the number of premature deaths caused by the disease.
- Once infected, there is no cure for HIV and AIDS. Treatment options include treatment of opportunistic infections, as they arise, and the use of ARV medicines.[38] For poor people living with the virus, access to public healthcare facilities is of paramount importance, as it is often the only way through which they can get basic treatment.
- Mere codification of socio-economic rights in the Constitution may be a good starting point towards the realisation of the rights of the poor. However, the enforcement and implementation thereof is what is required.
- Provision of adequate healthcare services must run alongside other human rights obligations, designed to improve the health and well-being of people living with HIV and AIDS. People need to be healthy in order to fully enjoy their constitutional entitlements. It is also argued that because the state is obliged to assist people who cannot access basic services through their own effort, it should prioritise programmes directed at the poor.

...unless all declarations, resolutions and commitments made with regard to HIV and AIDS are implemented, the fight against the pandemic will never end and millions more will die.

CONCLUSION

South Africa faces enormous challenges of poverty and unemployment. From the above, it is clear, that access to healthcare is, by no means, realisable for everyone in South Africa. Factors, such as stigma, discrimination, poor funding of the health sector, high costs of medication and a lack of an enabling environment, further aggravate

the challenges of access to adequate healthcare, treatment, support and care. This seems to indicate, that unless all declarations, resolutions and commitments made with regard to HIV and AIDS are implemented, the fight against the pandemic will never end and millions more will die.

The Court has not accorded adequate protection to the very basic survival needs of vulnerable individuals and groups, since it has primarily taken an approach that leaves individuals with very little hope of obtaining individual relief.[39] In its approach, the Court has limited itself to compelling the state to fulfil the obligations determined by the state itself, whereas it is, arguably, the duty of the Court to examine the compatibility of public policy with regards to its effectiveness towards the realisation of the right.

Certainly, litigation challenging the validity of government programmes, and the constitutionality of such decisions, is an enticing option. However, litigation is prohibitively expensive and, thus, out of the reach for most public interest groups, let alone individuals. Litigation can also drag on for a number of years, without affecting the status quo in the interim. Not all affected persons are heard, therefore, decisions are formulated in a general form that would accommodate as many as possible. Thus, there is little or no individual claim created by positive judgments in favour of the poor.

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Hermann Reuter

Lusikisiki: A model of best practice

Introduction

The Lusikisiki programme set out with the difficult task of implementing anti-retroviral therapy in one of the poorest and most densely populated rural areas of South Africa. It is a partnership between MSF (Doctors Without Borders), the Nelson Mandela Foundation and the Eastern Cape Department of Health.

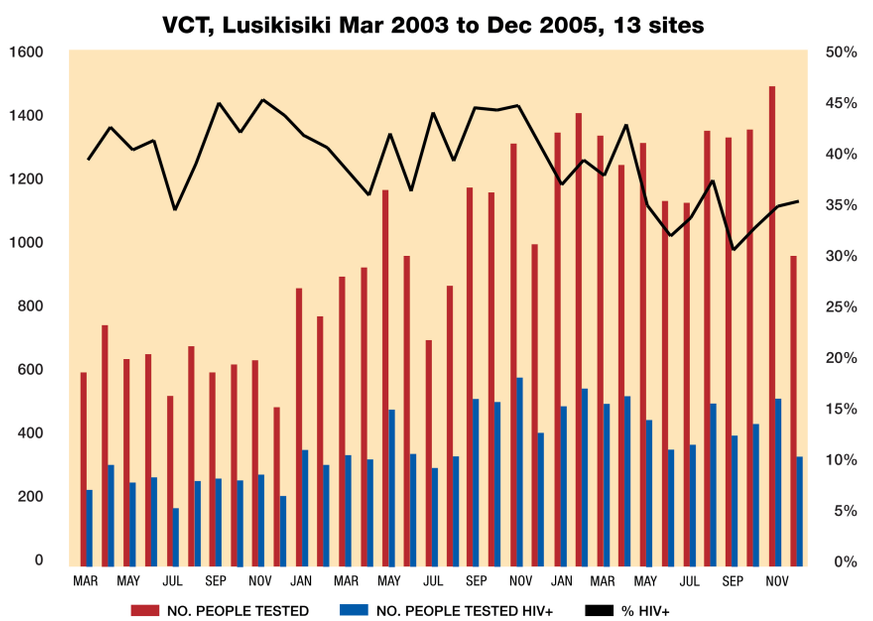
The conviction of the programme was that anti-retroviral (ARV) care in rural settings will not be effective if it remains the work of doctors in hospitals. To have a significant impact at the community level, ARVs must be provided at clinic level, using a nurse-based approach.

The programme has proven that a simplified, decentralised approach is highly effective. Experience over the last two years has shown that anti-retroviral therapy can be effectively scaled up at clinic level, and that patient outcomes in the clinics are comparable to those in the hospital.

Diagnosing an epidemic – Voluntary Counselling and Testing (VCT)

In 2005, the number of people tested increased 29% over the previous year – from 11,874 in 2004 to 15,366 in 2005. The average percentage of people who tested HIV positive was less than the previous year (35% versus 41%), but because of the increased number of testing done an additional 633 people were diagnosed HIV positive (5495 in 2005; 4862 in 2004; 2562 in 2003). In the beginning, mainly sick people were tested for HIV (with a higher rate of HIV infection), whereas now many healthy people (with a lower rate) come voluntarily for testing, resulting in the apparent decline in HIV rate.

The rapid increase in VCT is indicative of a reduction in stigma within the community. People are more willing to know their status. This can be attributed to the success of the ARV programme – people accept to be tested, because they know they can be treated – and



The red columns represent the increasing number of people testing. The shorter blue columns represent the people who test HIV positive. The black line represents the declining percentage of people who test positive.

also to work at the community level to encourage people to know their status.

Department of Health directives stipulate that counselling can be done by counsellors, but testing must be carried out by nurses. However, given the critical shortage of nurses – around half of nursing posts have been vacant since the start of the project – and the fact that the patient load will only continue to increase in coming years, the task of carrying out VCT should be shifted to the work of the counsellors.

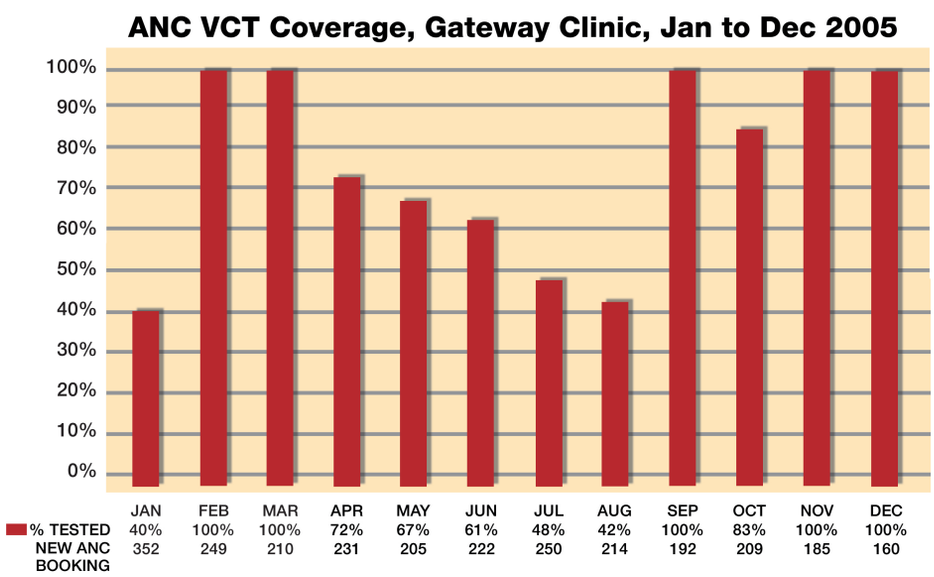
Preventing Mother-To-Child-Transmission (PMTCT)

The PMTCT services were introduced by MSF, but are now run by the Department of Health. 70% of nurses have undergone PMTCT training, at least one from each clinic.

PMTCT coverage is above 80% at most clinics, but needs improvement at others.

The goal of the programme is that all pregnant women are offered VCT, and all HIV infected women are assessed for CD4 count and fast-tracked onto ARVs, when their CD4 count is lower than 200.

The overall aim is to prevent childhood HIV infections, but there are several other advantages: raising awareness and knowledge about HIV, increasing coverage of VCT, enabling early management of opportunistic infections, and increasing access to ARVs for pregnant women.



This graph of Gateway Clinic clearly shows a problem occurring between April and August, which after intervention could be rectified.

... given the critical shortage of nurses – around half of nursing posts have been vacant since the start of the project ... VCT should be shifted to the work of the counsellors.

Challenges:

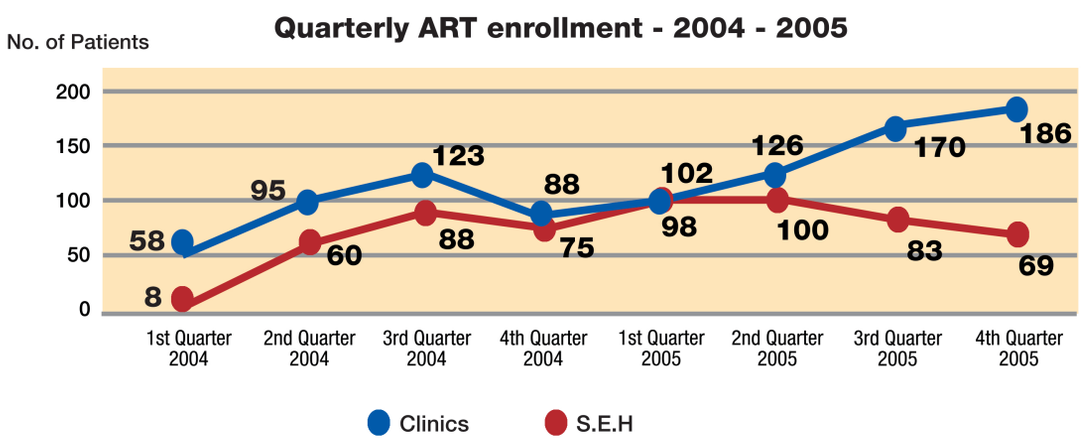
- High fertility rates pointing to insufficient family planning services and poor usage of condoms.
- A more effective protocol using AZT and a single dose Nevirapine, as opposed to Nevirapine only, has not yet been approved due to operational reasons.
- Many babies fail to be tested pointing to an urgent need to implement routine PCR testing, which can be done from six weeks onwards.
- Some clinics only provide four tins of formula milk per month instead of the eight needed, apparently due to fears of possible stock shortages.

Treating HIV with anti-retrovirals (ARVs)

Lusikisiki has a population of about 150 000 people, with an estimated HIV infection rate of 15%, that is 22 500 people living with HIV. If 10% of these are immediately in need of ARVs, it means that 2 250 people are in need of ARVs. The Department of Health currently provides ARVs to 1 529 patients (68% coverage in two years). Of these, 948 patients receive ARVs through twelve clinics and 581 through the hospital. Enrolment is increasing faster in the clinics because of multiple service points and services being integrated into general consultations and not dependent on HIV specific staff.

CD4 count on initiation has risen. At the start of the programme (early 2004), 50% of patients at hospital and 40% at clinics had a baseline CD4 <50 cells/mm^3; by the end of 2005 this had dropped to 20% at both hospital and clinics. This is an indication that access to ARVs has improved so that people are now recruited at a less advanced stage.

The CD4 and viral load of each patient is tested every six months. Apart from monitoring the individual's own health, these test results can also be used as a measure of the programme as a whole. All patients are divided into cohorts according to the date of starting ARVs. These cohorts can then be compared with one another and with other facilities. Patient retention measures how many patients are still on ARVs after the cohort has completed six or twelve months of treatment. Thus, service users who die, or that are lost to follow-up, or that decide to stop ARVs, will not be on ARVs anymore. Patients that are transferred to other facilities are not counted as part of the cohort. Retention at clinics is 83,3% after six months and 80,2% after twelve months. At the hospital, 75,6% of patients are retained on ARVs after six months and 68,6% at twelve months. This higher drop-out rate at hospital can be due to sicker patients starting treatment, patients having to travel further, due to higher numbers less individual engagement of health care provider with each service user, less reparation of ARV users, no community care givers to follow-up on patients, who do not return for appointment dates.



In the last quarter of 2005 (October to December) the hospital enrolled 69 patients while the clinics enrolled 186.

Lusikisiki has a population of about 150 000 people, with an estimated HIV infection rate of 15%, that is 22 500 people living with HIV.

Patient outcomes, on the other hand, are comparable at hospital and clinics. At clinics and hospital 70% of patients have CD4 counts more than 200 cells/mm^3 and 91% of patients have undetectable viral loads after six months.

Clinic-based ARVs versus down referral

In Lusikisiki, uptake can be increased rapidly and loss to follow-up reduced by decentralising initiation of ARVs. Less professional staff are needed, with doctors being almost entirely replaced by nurses, and community counsellors carrying a significant part of the workload.

A buzz-word in South Africa's ARV program at the moment is *'down referral'*. When the ARV roll-out started, it was based at hospitals. Now, service points are saturated and waiting lists are getting longer. So there is discussion about a more decentralised system, like Lusikisiki, where there is no waiting list. On the surface it seems like programme managers who motivate for down referral are following the model of Lusikisiki. However, on closer examination there might be flaws with the concept of *'down referral'*.

Generally, down referral means that ARVs should be provided at clinic level.

Does this mean service users are being prepared, started and monitored for ARVs, all at clinic level? Or does '*down referral'* imply that service users all start ARVs at hospital and then get referred to clinic after six months? If this is *'down referral'*, it does not follow the Lusikisiki model but opens the way to a situation that will be difficult to manage.

Most TB patients, who are lost to follow-up, are lost when diagnosed in hospital and started on TB drugs at hospital which do not get followed-up at clinic level. Will we see the same with *'down referral'* of ARV patients? This *'down referral'* model also implies that service users have to go to hospitals every six months to repeat their ARV prescription (by a doctor). Confusion is likely to occur; medicines get sent per named patient to clinics, however, every six months these medicines have to be sent to hospital and not to clinics. With a supply chain that is already tested to its limit, this extra complication will unlikely be managed. A further confusion will be with monitoring; at six months CD4 and viral load need to be monitored, so the blood is taken at the hospital. However, where do the results go – hospital or clinic? Routinely, results of tests taken at the hospital would come to the hospital. However, the patient will only return to the hospital after six months. If the results were to be sent to the clinic, then nurses at the clinic would need to be trained to take

At clinics and hospital 70% of patients have CD4 counts more than 200 cells/mm³ and 91% of patients have undetectable viral loads after six months.

appropriate decisions based on these results, and then there would be no reason for the patient to have to go to hospital in the first place.

An unresolved problem of this *'down referral'* model is also who keeps the outcomes report on the service user? If blood tests are done at the hospital, then hospitals should report on the six-monthly outcomes, yet the clinics are the institution mainly treating the patient. So as soon as outcomes are poor, the blame will be placed on the clinics. On the other hand, clinic staff will not be motivated to do their best, as they will not be monitored on the outcomes of the programme in any case. For the chronic management of an illness, only one institution should carry the responsibility. According to the Lusikisiki model, this should clearly be clinics.

Providing ARVs on the model developed in Lusikisiki requires that a good laboratory courier system is developed for clinics (especially in rural areas); that nurses are sufficiently trained to manage opportunistic infections and the basic ARV protocol and are authorised to initiate ARVs; and that clinics have enough staff.

Some people argue that this is not possible due to lack of infrastructure. On the other hand, this provides the perfect reason of why primary care infrastructure should be prioritised now, as outlined in health policy since democracy. Other people argue clinics cannot initiate ARVs as there are no doctors at clinic level. On the other hand, ARV provision should not be slowed down due to perceived need of doctors to initiate ARVs. What prevents nurses from being empowered to initiate ARVs? This is a basic decision based on very clear guidelines that professional nurses can quickly learn once given the scope.

It seems like the *'down referral'* model underlines the status quo, rather than pointing to the way in which the Department of Health should develop, driven by the need of the HIV epidemic.

Community mobilisation

The HIV programme in Lusikisiki relies strongly on community mobilisation. This was important to create awareness, break the stigma, and to ensure good patient preparation for, and adherence to, ARVs. Treatment literacy provided by adherence counsellors at clinics, and by the Treatment Action Campaign, through its twenty two branches in the community, is an essential component.

There is also an active condom distribution campaign that distributes an average of 120 000 condoms per month at distribution points in the community, including shops, schools and taverns.

However, health promotion does not limit itself to awareness, life-skills and condom distribution, but, in the spirit of the Ottawa Charter of Health Promotion, it also promotes:

- Building healthy public policy;
- Re-orienting health services; and
- Strengthening community action.

It seems like the *'down referral'* model underlines the status quo, rather than pointing to the way in which the Department of Health should develop, driven by the need of the HIV epidemic.

Thus, support groups, clinic service users and community members are empowered to such a level, that they can participate in discussions about promoting clinic-based ARV services; the need for adherence counsellors; the need for a more effective PMTCT protocol; implementing routine testing of HIV-exposed babies with a PCR test; preferably using fixed dose combination (FDC) ARVs than the present separate drugs; and the need for a good drug supply. These topics were eloquently discussed by ARV users at the two-year anniversary of the ARV programme, which celebrated 1000 people using ARVs, and in campaigns pushing for better services.

The rural community also participates in ARV Adherence Committee meetings that evaluates the social conditions of all ARV users anonymously, and decides on who needs more support. Clinic Committees have also helped to speed-up improvement of clinic infrastructure through renovations and a campaign to have Anglo Gold Ashante mining company donate its private clinic in Lusikisiki to the Department of Health.

Conclusion

A pilot project like this faces three challenges:

a) create an effective, viable model

b) get it approved and implemented on a broader scale

c) ensure sustainability of the services after the pilot period is over

The model of delivery of ARVs is well established in Lusikisiki. The UNAIDS programme has identified the programme as a model of best practice. The model has helped to influence the ARV services in the Eastern Cape where a high emphasis is placed on clinic-based ARVs. However further policy approval for allowing nurses to prescribe ARVs, and counsellors to do HIV testing, needs to be clarified. Due to careful integration of the HIV services into existing clinic services, it seems possible that MSF can leave Lusikisiki by the end of 2006, without interruptions to services for people living with HIV.

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Susie Clark

ARVs versus Social Grants: **The Dilemma of the Poor**

Abraham Mazibuko is a small, frail-looking man who looks older than his 37 years. He was diagnosed with HIV in 1999, and qualified to receive a Disability Grant shortly thereafter.

Abraham lives in Orange Farm, one of Johannesburg's more impoverished townships. Even before he became too sick to work, he had never had a job. None of the 10 family members, he shares a home with, are employed either. Thanks to his Disability Grant, Abraham became the family's primary breadwinner. His R780 a month stipend put food on the table. But, in July of last year, Abraham received a letter from the Department of Social Services, informing him that his grant had been stopped, and that he would have to go to his local clinic for a medical assessment before reapplying.

Until about a year ago, HIV and AIDS patients in South Africa generally became eligible for a Disability Grant, when their CD4 count dropped to below 200. All Disability Grants were supposed to be reviewed on a regular basis, but lack of capacity meant this often did not happen, leading to a widespread perception among recipients that their grants would continue indefinitely. The combined impact of an HIV epidemic, that is estimated to have infected 21.5% of the adult population, and an unemployment rate, which has sky-rocketed over the past decade to over 35%, has seen the percentage of South Africans accessing Disability Grants rise between 2000 and 2004 from 1% to 8%. This, linked with government concerns surrounding fraud, caused the Department of Social Development to begin implementing its review process more rigorously, and to rely on a doctor's assessment of the patient in addition to a CD4 count.

Abraham went to his doctor for the required assessment, but his grant application was declined, and three attempts to appeal the decision have not succeeded.

Abraham is one of approximately 110,000 South Africans now receiving free anti-retroviral (ARV) treatment through a government programme that began rolling out in November 2004. It is among the largest government-sponsored anti-retroviral programmes in the world, but according to figures released late last year by UNAIDS and the World Health Organisation[1], Abraham is still one of the lucky few. As of December 2005, 85 percent of the 750,000 HIV-infected South Africans in need of ARV drugs had yet to begin receiving them.[2]

It was probably the ARV drugs that improved Abraham's health sufficiently so that he no longer qualified for the Disability Grant. In other words, Abraham now has access to life-prolonging medicine, but no money to provide for his basic nutrition. In addition, he is feeling the stress of no longer being able to provide for a family, which includes four children orphaned by the deaths of his brother and sister.

Despite his doctor's assessment, Abraham is far from a picture of health. He can no longer afford medicine to treat a persistent hacking cough; nor can he afford to take mini-bus taxis (the only mode of public transport available in many parts of South Africa); and his feet have become painfully swollen from the daily walk to and from a community-based HIV and AIDS drop-in centre, where he receives a free meal.

'I come here to eat, because I have no food at home', he says.

Sheila Mphuting, who runs the centre called Tjhebelo-Pele, meaning *'Look Forward'*, says she has seen an increasing number of her clients lose their Disability Grants, since the local clinic began distributing ARVs, and Social Services began cracking down on its review process. *'It's like they're killing people purposely because if you stop the grant, how are these people going to look after themselves?'* she says.[3]

After 11 years running an HIV and AIDS organisation in Orange Farm, Mphuting knows very well that, in many cases, the best way to help people living with the virus is simply to feed them and argues that *'we can see that people aren't dying from the disease, but from starvation'*.[4]

...85 percent of the 750,000 ... in need of ARV drugs had yet to begin receiving them.

Mphuting wonders at the seeming lack of communication between a health department, that advises patients never to interrupt their ARV treatment, and a social services department, that effectively penalises people for following that advice.

Currently, a relatively small number of people living with HIV and AIDS are affected by these conflicting policies, but Nicoli Nattrass, a professor of economics at the University of Cape Town (UCT) and director of the UCT AIDS and Society Research Unit, predicts that unless the government addresses the issue, by 2010, when it is expected that all South Africans in need of ARV treatment will be accessing it, the large scale loss of Disability Grants could precipitate *'a social crisis'*[5]

The Disability Grant is the only form of social security available to working-age adults in South Africa. Not surprisingly, given the high levels of unemployment and HIV prevalence, it has become, what Marlise Richter of the AIDS Law Project calls, *'a de facto poverty alleviation grant'*.[6]

Richter's colleague, Chloe Hardy, completed a preliminary study[7] in 2005 that looked at to what extent people depend on their Disability Grants, and what it would mean for people and their families to lose the grant.

The study found, that as well as offering people living with HIV the possibility of a longer life, access to ARVs presented them with a terrible dilemma.

'For someone with HIV, who's been the breadwinner in terms of being able to access this grant, they are at a crossroads where they either continue accessing the grant and don't continue with ARVs, or access ARVs and get booted off the grant', Richter says.[8]

The AIDS Consortium, an umbrella NGO that brings together over 1,000 community-based AIDS organisations in South Africa, has assembled a social grants task team, partly in response to the crisis that Nattrass predicts. Reports from member organisations of clients on ARV treatment losing their Disability Grants have started to trickle in. So far, there have been no known cases of people choosing to stop treatment in order to continue receiving the grant. Mphuting, however, says she does have one female client with a CD4 count of just four, who has refused to begin treatment, because she is so fearful of losing the grant, she relies on to support her three children.

'They panic, because that [grant] *money makes a big difference to their families',* Mphuting says.[9]

The grant dates back to the apartheid era, when it was assumed that having regained one's health, individuals would return to work and be able to support themselves. But, according to Hardy[10], most of the individuals, interviewed for the AIDS Law Project study, had been unemployed even before they became too sick to work, and some, like Abraham, had never held a permanent job. Hardy states that '*by getting the disability grant their family's economic situation improved significantly'.*[11]

Supporting this finding, another study[12], conducted in the Cape Town township of Khayelitsha, found that in households containing a disability grant recipient, the grant made up as much as 41% of the family's total income.

...a health department, that advises patients never to interrupt their ARV treatment, and a social services department, that effectively penalises people for following that advice.

Healthcare workers and caregivers worry that the loss of the Disability Grant could have disastrous consequences, not only for family budgets, but for the health of their HIV infected patients.

Toni Gloria, an affiliate of the AIDS Consortium, who runs a community-based organisation for people living with HIV and AIDS in Soweto, says that five of her clients have lost their grants in recent months. *'When the grant stops, there's no food. They start to get stressed and then they get sick',* she says.[13]

Speaking from the HIV/AIDS Clinic at

... South Africa's welfare system too closely resembles a *'lottery'*... families *'lucky'* enough to include a pensioner, a child under 14 years, or someone sick ...have access to social security.

Helen Joseph Hospital in Johannesburg, Sister Sue Roberts confirms that without grant money, many of her patients cannot afford the cost of travelling to the clinic every month to pick up their drugs. She also fears that, without the grant, they will not be able to follow the nutritional advice they have been given.[14]

The government's treatment plan includes a nutritional component, but, according to a report released last year by the Treatment Action Campaign, implementation has so far been *'fragmented, uneven and beset by problems'*.[15] Only the malnourished qualify for nutritional supplements, and government-issue food parcels are only provided to patients as a short-term measure and then, only sporadically.

Several participants in the AIDS Law Project study described how their health had improved, since they started receiving Disability Grants, because they were able to buy healthy foods, they previously considered unaffordable. Some expressed concern that, without the proper nutrition the grant gave them access to, they would become sick, even with ARV treatment.[16]

Several groups have pointed out that South Africa's welfare system too closely resembles a *'lottery'*, in which only families *'lucky'* enough to include a pensioner, a child under 14 years, or someone sick enough to qualify for the Disability Grant have access to social security. The Treatment Action Campaign, the AIDS Consortium, the AIDS Law Project and COSATU (South Africa's largest trade union) are among a number of organisations that have formed a coalition to support the introduction of a Basic Income Grant (BIG) for all South Africans, regardless of their HIV status. Coalition members argue that a basic monthly grant would remove perverse incentives to become HIV positive, or to refuse ARV treatment, and provide equally for all families in need of support.

Nattrass estimates that providing the subsistence-level grant would require an increase in taxation equivalent to an extra 8% on VAT. *'The point is, there's going to be a tax burden and we all have to share it'*, she says.[17]

Chief Director of the Department of Social Development's HIV/AIDS Unit, Dr. Connie Kganakga, acknowledges that there are problems surrounding the Disability Grant, but says that the Basic Income Grant is *'not yet on the table, for reasons that the government can't afford it right now'*.[18]

But, Pumi Yeni, national organiser of the BIG Coalition, argues that BIG could actually save the government money in the long term, by postponing the need for ARV treatment. Yeni[19] states that:

> *If you give people food you're ensuring a healthier nation, so obviously by introducing a Basic Income Grant you're giving all those HIV positive people whose CD4 count hasn't dropped to 200 a chance to go on longer before they need ARVs.*

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Emma Harvey

Home-Based Care: Realities and challenges

According to the Department of Health (DOH), 40,000 volunteer home-based care (HBC) workers are already active in South Africa, and plans are in place to recruit 122,000 more volunteers in the next five years. These volunteers are paid a stipend, ranging from R1 000 to R1 700 per month[1], and are often trained and managed by NGO's contracted by the department.

INTRODUCTION

High rates of unemployment and poverty in South Africa mean that an opportunity to earn R1 000 to R1 700 per month as a volunteer HBC worker would constitute a significant amount of a household income, which otherwise might not exist at all. Mbambo [2005][2] argues that many previously unemployed volunteers see voluntarism as a way to access employment. Though voluntary HBC may become an important access to income for many households, not much attention is paid to the challenges experienced by the HBC workers, including facing stigma in their communities, overworking, often working without access to necessary training and resources, and the intense emotional and psychological stress that the work entails.[3]

RESPONSIBILITIES

HBC workers are generally responsible for basic nursing care, though not prescribing or administering medication. As one HBC worker describes the situation:

> *We are aware that our service is not sufficient. At times we find people that are in pain. We cannot offer those people a single painkiller because we have nothing to give them. The government must provide us with medical kits with common tablets that don't need any prescription. It is not enough to clean the house and cook food for a sick person and then leave him/her in pain. We go to the river to wash their clothes and also give them a bath, but the pain is still there. The government must do something about this. Our service is not complete.* [Campbell et al, 2005]

Van Dyk [2001:329][4] identifies the lack of knowledge of medicine, disease and treatment as the *'potential problems'* for HBC work. It also seems that in many cases basic resources, such as gloves, disinfectant and cleansing materials are not available to volunteers. This seems to raise the question of whether or not HBC volunteers provide adequate healthcare, especially since there is not enough collaboration between HBC volunteers and professional medical personnel to ensure that the needs of patients are well looked after.[5] Cullinan [2000] puts it eloquently when she argues:

> *...if state health facilities are simply going to discharge AIDS patients and assume that they will be cared for at home, HBC will simply be a brutal form of privatisation where the poorest communities are expected to bear the greatest burden of the epidemic.*

Generally though, there are still questions about the training of HBC workers, and even if their job is to only provide basic nursing care, whether or not the skills imparted are enough. Cullinan [2000] argues that some DOH training is only five days long, as compared to six month training provided by an NGO doing HBC work with volunteers.[6] With training of five days or more, the question remains whether or not HBC volunteers can be fully trained in the skills necessary for the work, and whether or not any attempt is made to raise awareness of the importance of fundamental rights, such as the right to confidentiality, and to non-discrimination.

STIGMA

Stigma still affects both the HBC volunteers in their approach to patients, and the HBC volunteers themselves, who face stigma in their communities, because of the work they do. An extreme example of the measures taken in order to avoid the potential stigma is a training course run in a city with a high prevalence rate where the word *'AIDS'* is not used at all.[7] Some programmes have shifted their focus from starting out focussing solely on HIV and AIDS to including other illnesses, such as TB and cancer, in an attempt to overcome stigma in communities that hampers the delivery of care. Another example is the reluctance of HBC workers to join treatment programmes, out of fear of participating in the same ARV programmes as their clients, in case community members get to know about their HIV status.[8]

GENDER

HBC volunteers tend to be largely women.

Women are generally the caregivers in households, and this is extended to doing more *'women's work',* including household chores, while caring. The fact that HBC volunteers are generating income for their households also introduces an interesting dynamic, since the type of work is typical of gendered roles. The work itself is not highly valued and does not get much public recognition in communities. An interesting argument, though taken from Zimbabwe, could equally apply to South Africa:

> *If men participate more in home-based care, it may reduce the stigma that is often faced by people living with HIV and AIDS. Their involvement would send positive signals since many people take more notice of what a man says than a woman.* [Dongozi, 2005]

...HBC will simply be a brutal form of privatisation where the poorest communities are expected to bear the greatest burden of the epidemic.

...many volunteers... use their own scarce resources to care for, feed ... and pay for funeral costs of people that they are caring for.

The continued undervaluing of women's work, and the fact that communities *'take more notice'* of what a man says, signals that there is no formal or substantive equality around the issue of who does home-based caring.

IMPLICATIONS

Although some organisations have developed detailed policies on volunteer management, there is no enforceable legislation, or departmental guideline, that regulates volunteer management and, because of this, in many cases there is no recourse for volunteers when their rights are violated. Additional burdens are carried by some HBC volunteers, as the care work that they are doing limits their opportunities for job searches, and according to Akintola [2004:4][9] many volunteers are not even accessing the stipend and use their own scarce resources to care for, feed and sometimes clothe, transport and pay for funeral costs of people that they are caring for.

As and when exploitation of the volunteers takes place, it might be a difficult choice in some households to weigh up the value of the income versus addressing any violation of the rights of the HBC worker, because of the *'stipend'* that is paid.

The question of protection both for the volunteers and the communities and people they serve is a vital one. It is clear that some form of national or DOH policy that draws on the experience of current HBC programmes, is necessary, so as to ensure that the rights of volunteers, and the people they serve, are protected.

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Nkomazi: Where to from here...?

Heather McKallin

Nkomazi: Realities and demographics

Consider the following:

- The Nkomazi Voice, a weekly community newspaper servicing a rural population in Mpumalanga, reported the following stories in their 3rd March 2006 issue:

  '16 year old rapes 13 year old', '15 year old raped in the bushes', '14 year old raped 5 times', '4 year old raped', 'Biological father rapes his daughter', '23 year old raped', 'Mother narrowly missed being raped by her son' – accompanied by a police statement saying statistics now show that 3 out of every 5 women have been raped, while one education circuit covering 13 high schools reported that 324 learners fell pregnant in 2005.

- A few issues prior to this, the newspaper reported doctors from the local hospital saying that the Nkomazi region experienced an HIV infection rate of approximately 47% amongst the sexually active population.
- One NGO working with AIDS reported that they make an average of 20 coffins a month to service only their patients.
- There were no hands raised when a group of children, aged between 6 and 10, were questioned on whether they had breakfast, maybe 20% indicated they had lunch and only 80% had supper every night.

A few years ago, the above information would have illicit gasps of shock, expressions of disgust, anger, sympathy, or, perhaps, even shame. No more. The deafening silence bears testimony to the protective shroud of complacency that the community is wrapping around itself as a self-defence mechanism in facing a dilemma without a solution.

The horrific significance of this non-reaction is that the Nkomazi community and, perhaps, society in general, has become immune to the social deprivation implicit in these situations. People are no longer shocked at abuse, they ignore the HIV figures under a fatalistic approach to death, and funerals are no longer a time for deep mourning. As for poverty, for some it is a situation from which to claw their way out by any manner possible, whether morally legitimate or not, or for others, a situation so filled with hopelessness that they merely exist, not caring what happens to them. This latter situation spurring many women to abdicate from a platform of self-respect, and for a few Rands, succumb to brutal physical, psychological and emotional abuse from unscrupulous men who prey, with impunity, on their vulnerability.

The Nkomazi community occupies a small finger of land that juts down from the southern border of the Kruger National Park and borders on Swaziland and Mozambique. This approximately 250 sq/km of land is home to an estimated 800,000 people living in 34 villages. It lies 100 kilometres east of Nelspruit and on its eastern border is the notorious electric fence built during the years of war in Mozambique, which is still 'live' today. Nkomazi's prime claim of tourist interest is the monument erected to Samora Machel commemorating an African leader, who is seen as an icon of the struggle in the liberation of Africa. The monument itself epitomises the character of the Nkomazi community. Set on a desolate and barren mountain, hollow tubes play mournful music as wind swirls around them, the notes, a grim reminder of the futility of the war.

The Nkomazi community stems from the previous homeland called Kangwane. Few communities demonstrate the raw results of historic blunders as blatantly as the Nkomazi community.

Firstly, the border with Swaziland divided families to such an extent that the chief of Matsamo divides his time between the two countries and, with the cultural and economic development of the two countries moving at different speeds, along with his traditional

leaders, he struggles to relieve the abnormal tensions, which arise in families split apart by an arbitrary line drawn on a map thousands of miles away. A particular challenge now facing the community is the rise in numbers of vulnerable children, who would naturally live with an extended family when necessary, but who are now unable to do so, due to the legal requirements of the two countries. Cross border *'appearance'* and *'disappearance'* of children are frequent.

Secondly, the 15 year long Mozambique war resulted in thousands of refugees pouring into the area seeking shelter and employment.

Thirdly, the Apartheid government re-settled hundreds of displaced people in this remote area and developed a 20 km belt of strong white-owned commercial sugar, citrus, vegetable and game farms along, what is now, the N4 Maputo corridor running between Malelane and Komatiport. These farms provided employment to the local population, but also attracted immigrants, both legal and otherwise from the neighbouring countries. The influx of people across the borders continues, adding further burdens to economic and infrastructural development of the area. Many of the people have relatives in Nkomazi and, thus, have a starting base, but they leave their own families in their country of origin and start new families in South Africa. However, the South African families themselves are often in desperate situations and are forced to live in poverty. Children born of these families are vulnerable and some are abandoned. Disease often plagues the families due to their living conditions. Parents, who then die as illegal immigrants, leave their children with no legal status or visible means of support.

And lastly, with the advent of democracy in 1994, the socio-political dynamics of the commercial farming sector in Malelane and Komatiport changed from being white run to black run, raising racial tensions that simmer under the surface of an otherwise relatively peaceful community. Unfortunately, Nkomazi experienced a 'brain drain', with better skilled people being deployed in provincial government, leaving a municipality that sadly lacks the ability to deliver. This resulted in the Nkomazi local government being placed, in 2005, under special curatorship with the national government's Project Consolidate. Reports of corruption and scandals have continued to surface, deflecting energies and attention from delivering much needed infrastructure and further fragmenting a society struggling to find its own identity.

Traditional leaders and healers still play a pivotal role in the community, although their authority is being eroded with improved education and economic independence of the people. Loyalties of the youth vacillate between adhering to cultural and traditional norms and following the modern trends seen on TV and heard on radio. The society continues under a strong male chauvinist influence. A high percentage of women show fortitude and strength in their ability to nurture and care for children, albeit under difficult and strenuous situations. However, most women still shrink from engaging in activities that involve peer competition with males. For example, in community meetings, it is still common for women to sit on one side and men on the other with few women contributing. Women have held government posts, such as mayor of Komatiport, and a representative in the Mpumalanga legislature, but one wonders, if the appointments were a sop to meeting quotas, or genuine reward for ability.

The major employer in Nkomazi is the government, supporting 134 schools, 20 clinics, 2 hospitals, and the public works programmes, as well as Eskom and Telkom. The annual municipal salary budget is R80 million, excluding educators and health workers. Only a small number of sub-standard RDP houses have been built. Some improvements to schools are visible, but the community is angered by the general lack of infrastructure delivery, particularly in road maintenance and provision of water. Electricity has been installed in approximately 50% of homes and communication through cell phones is common place. There is limited access to the internet. The only local employment is on farms and with a few retailers. The area has two shopping centres, with a Spar and a Score and furniture chain stores. There are no industries in the area apart from the TSB (Transvaal Suiker Beperk), a sugar mill, which employs approximately 2 400 people. Both the recent climatic changes, drought last year and near floods this year, and government legislation surrounding farming and land issues, is resulting in waves of retrenchments

from the farms, thus, contributing to the over 70% unemployment rate in the community.

Unemployment and poverty, combined with the impact of HIV and AIDS, are the major challenges facing the community.

However, the façade of the community presents a different picture. Driving along the main road from Malelane to Piggs Peak, in Swaziland, one would be forgiven for thinking that the reports of poverty are exaggerated. The houses built by government employees, and contractors, would sit comfortably in any A-income suburb of Johannesburg. But delve just 500m behind, and the sight of single mothers lying sick in shacks, while being cared for by their children is not uncommon.

It is estimated that 53% of the population is under the age of 19. More than 70% of families are *'dysfunctional'*, including single parent homes, children living with extended families (mainly grandparents), and mothers with children from more than one man. There are still an above average number of teenage pregnancies, with many of the girls dropping out of school to give birth. Sexual activity starts from as young as 12 years old. Abuse of children, rape and incest are reportedly way above the national average.

The above paints a morbid picture of a society impacted by influences from many different quarters. But the capacity of the human spirit to overcome this is strong and many positive success stories can be told.

Efforts to address the realities of Nkomazi

Thembalethu Home-Based Care (THBC), an NGO founded in 1999, has adopted a holistic approach to the community needs, which are exacerbated by poverty and HIV and AIDS. THBC offers a real, and tangible, holistic solution through four focused activities, namely home-based care, orphan and vulnerable child care (OVC care), HIV and AIDS prevention (Youth in Action), and food gardens. The specific demographics, and community dynamics, dictated the best approach to successful implementation of the projects, and THBC has adopted a 'best fit' policy to its operations. THBC's positive impact on the community has won support from local, national and international organisations.

THBC's work, which targets the lower income groups, stretches over 20 villages and directly benefits 400 people monthly with secondary beneficiaries of approximately 10,000. However, the programmes reach the whole community.

The home-based care division offers palliative care through a network of 300 care supporters, who have been trained in first-aid, first level primary healthcare, and in trauma identification and counselling. The network is supported through the head office, by specialist co-ordinators, who have graduated from being care supporters. Over 8,000 patients have been assisted through the home-based care programme. Destitute families are provided with basic food and encouraged to start a food garden. In the event of a death, a coffin is offered and THBC conducts the funeral.

Children who are left are continually cared for by the care supporter. THBC has over 300 orphan-headed homes. These are homes where the eldest child can be from 14 to 25 years old and looks after 3 to 4 siblings. THBC has over 4,000 children on its data-base, and offers an after-school programme, feeding schemes and special one-week trauma counselling and life skills training programmes for orphans. 17 small brick homes have been built and many more repaired. Children are also assisted with school issues and uniforms, and first level medical care.

THBC offers assistance with obtaining legal documents for the children, so that they can receive government child grants. This process is long and tedious and fraught with frustrations, especially when the parents had no documents, or if the parents cannot be found and the children were left with the grandmother, who, in turn, has no papers. The issue of land/home ownership for orphans is a thorny one, as modern norms clash with traditional practices. In the past, when a husband died, the house reverted to his family, many of whom threw the widow and children out. THBC in conjunction with TRAC (The Rural Action Committee) in Nelspruit, is working on obtaining legal possession for the orphans, as part of their inheritance.

The government's child grant system, a lifesaver in itself, is spawning a culture of negative independence amongst the youth. Without adequate training and

management, the eldest siblings are using the money to purchase cell phones, TV's and other luxury items, while the younger members go hungry, unclothed and unfed. A family of 5 children can receive over R2000 per month. Care supporters are turned away from the house, and there are too few social workers to handle all the cases. Some of the youth have had the ingenuity to become money lenders! THBC now runs workshops for the *'heads'* of orphan-headed households to provide capacity to run the homes.

In other situations, unscrupulous extended family members are gaining access to the grants on behalf of the orphans and then using them for their own children at the expense of the orphans.

The primary challenge faced in handling the HIV and AIDS issue is related to cultural and traditional practices. The influence of traditional healers and sangomas is very strong in each village. The traditional healers are steeped in the Swazi culture and do not acknowledge the reality of HIV, thus, when patients present with signs of HIV, or opportunistic diseases, the healer does not provide adequate medication and does not encourage HIV testing.

Men are reluctant to use condoms saying that they won't *'put a shield on my bull'*. Poverty drives young girls to offer *'sex for money',* and to fall pregnant in order to access the government grant.

There is still very strong stigma attached to HIV and AIDS. Although people are beginning to admit that someone died from AIDS, there are no role models in the community who have *'come out',* and this, in spite of the fact, that hundreds of people have been tested for HIV and that the hospital has currently over 400 people on ARVs.

The stigma stems from a number of issues. One of these is the reluctance of families to discuss sex openly. Thus, although parents may be aware of the sexual behaviour of their children, and even have knowledge that their partner is engaging in multiple relationships, they are in denial. Another powerful influence in propagating stigma is the belief that illnesses come from a curse. The fear of being *'witched'* or *'cursed'* permeates all aspects of society, spreading into the work environment and making open communication amongst team members difficult. Another example of stigma in the society, is the treatment of the physically and mentally impaired, who are *'kept hidden'*, for fear of people thinking that the parents have done something wrong.

THBC has introduced a number of initiatives to combat the onslaught of HIV and to address the situations described above.

The Nkomazi Voice was started as a means of teaching about HIV, while simultaneously encouraging debate, imparting knowledge, and offering a challenge to the community to participate in community building activities, such as sports, SMME development, improved education standards and general dialogue, and also exposing a number of myths. The paper prints weekly and has published 124 editions with an estimated readership of 40,000.

The Youth-in-Action programme, with the motto *'Challenged to take control'*, was launched as the HIV awareness and prevention programme, which focuses on the A & B message (Abstinence and Be faithful). The goal here is to offer youth an alternative lifestyle along with the message. Thus, a number of extra-mural and life skills activities have been established. 400 peer counsellors have been trained through the Center for the Study of AIDS. They are now establishing support circles in each village to encourage HIV testing. Clubs now run throughout the area offering Latin/American dancing; performing arts; cutting CD's with *'wannabe stars'*, our local version of Pop Idols; sports, including chess, volleyball and basketball; and debating. The youth have risen to the level of competing and winning in national competitions and are now running a YiA basketball league and a chess tournament, attracting over 100 children. Workshops are held regularly for all activities and the youth are becoming increasingly competitive and proud to be winners. This is contributing to rediscovering the value and dignity of each member of the community.

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Faustace Chirwa

HIV and AIDS in Malawi:
An analysis of treatment initiatives

Malawi registered the first HIV case in 1985. By 1998, the figure had risen to 365,000 and in 1999 to 735,000. Currently, nearly 1,000,000 people are said to be living with HIV. However, the epidemic, in addition to its direct impact on mortality, also has some secondary influence on death rates.

INTRODUCTION

The large increase in the number of orphans, the economic disruption of households, the increase in mortality from TB and other causes, could as well contribute to higher mortality and an even lower rate of population growth.

With the national adult prevalence rate at 14.4%, the impact is particularly severe amongst adults in the prime working ages, and amongst children under the age of five years. Current estimates show 80,000 children between 0 and 14 years are infected. However, AIDS has more than tripled the number of adult deaths to nearly 80,000 a year. Using 1998 population and housing census, life expectancy in Malawi was estimated at about 40 years, but if people were not dying from AIDS, the life expectancy would have been about 56 years.

POLITICAL WILL

As a member of the United Nations, Malawi has signed no less than 11 other previous commitments on HIV and AIDS. This is an indication of the seriousness that government places on the importance of stopping further HIV infections.

One of the commitments Malawi has signed is the UNGASS[1] Declaration of Commitment on HIV/AIDS (2001). However, the country has experienced some successes and difficulties in meeting the declaration targets.

The Declaration, in Section 47, says:

> *By 2003, establish time-bound national targets to achieve the internationally agreed global prevention goal to reduce by 2005 HIV prevalence among young men and women aged 15 to 24 in the most affected countries by 25% globally by 2010 (...).*

Malawi is considered one of the highly infected countries in sub-Saharan Africa.

The Declaration further states in Section 62:

> *By 2003, in order to compliment prevention programmes that address activities which place individuals at risk of HIV infection, such as risky and unsafe sexual behaviour and injecting drug use have in place in all countries strategies, policies and programmes that identify and begin to address those vulnerable to HIV infection, including underdevelopment, economic insecurity, poverty, lack of empowerment of women, lack of education, social exclusion, illiteracy, discrimination, lack of information and/or commodities for self-protection, and all types of sexual exploitation of women, girls and boys, including for commercial reasons. Such strategies, policies and programmes should address the gender dimension of the epidemic, specify the action that will be taken to address vulnerability and set targets for achievements.*

Malawi has joined other nations in implementing the UNGASS Declaration of Commitment on HIV/AIDS. Malawi, through the National AIDS Commission, can proudly announce to the world, she has responded positively to the Declaration, because the country has developed foremost, the National AIDS Policy, which has put in place preventive and mitigation strategies for HIV and AIDS, through prevention, care, support and treatment strategies. However, the challenges are many for Malawi to achieve the targets set by the Declaration of Commitment, as a response to the epidemic.

AN OVERVIEW OF THE HIV AND AIDS PANDEMIC IN MALAWI

Malawi's development as a country has been affected in many ways, as the country continues to lose human resources through the epidemic. Although Malawi is the hardest and highest hit country with AIDS, there is light at the end of the tunnel.

HIV and AIDS has taken a heavy toll on the population, where approximately three quarters of infections are found amongst adults, between the ages of 20 and 40 years.

There is growing commitment at all levels to fight HIV and AIDS; policy and institutional frameworks are in place; sufficient know-how has been acquired from the various initiatives supported over the years; and there is an increase in resources for HIV and AIDS. However, very little resources are reaching the Malawian children.

An HIV prevalence rate of approximately 16% in a population of about 10 million people in the 1990's, has now been estimated at about 14.4% for the year 2003. Yet, there is concern that there is a growing number of new infections taking place amongst some vulnerable groups.

Recent statistics in Malawi indicate that the highest infections occur amongst women and girls between the ages of 15 and 40 years. Prevention of new infections has been recognised as a major component in the halting of the pandemic, and the Declaration states prevention must be the mainstay of the response. In terms of maternal health in Malawi, statistics provided by the World Health Organisation (WHO), indicate that 418,000 women get pregnant every year; 1,150 women get pregnant every day; and approximately 50 women get pregnant every hour. Furthermore, 5,000 maternal deaths occur every year; 13 maternal deaths occur every day; and 1 maternal death occurs every 2 hours. The report also indicates that Malaria, Anaemia, Tuberculosis, and HIV/AIDS are indirect causes of maternal deaths. It is this vulnerable group (women) that is most at risk, in terms of being infected and affected by HIV and AIDS.

In Malawi, every year, approximately 40,000 newborn babies get infected with HIV, through mother-to-child transmission (MTCT), and of the estimated one million orphans, 500,000 have lost one, or both, of their parents due to AIDS.

Why give so much attention to the children? Everybody is aware that children are the future of any nation. Hence, their welfare should be a priority of any democratic government. Of utmost interest, is Malawi Government's commitment to the welfare of children, orphaned by the HIV and AIDS pandemic. In this regard, the Ministry of Gender, Child Welfare and Community Services launched a new Orphan Policy and a National Plan of Action on Orphans in June 2005. The Policy is helping the promotion of community-based orphan childcare centers, as opposed to institutional orphanages. The Action Plan would, amongst many other interventions, encourage food village banking as a means of ensuring food security at village and community level. In practical

terms, the communities are given agricultural inputs to grow various crops, and are encouraged to create food banks after harvest. The implementation of these interventions is what the country is yet to establish!

WINDOW OF OPPORTUNITY

As part of government's responsibility to ensure that all persons infected by HIV and AIDS live a normal life and access treatment in Malawi, the government, in May 2004, began providing free anti-retroviral (ARV) medication at public health facilities, hoping to reach 44,000 people living with the virus by June 2005.

90 health facilities are currently providing ART in Malawi with funding from the Global Fund. Of these, 60 health facilities, including all Central, District and major Christian Hospital Association of Malawi (CHAM), Malawi Defence and Malawi Police hospitals, will provide free ART, while the 30 private sector health facilities will provide ART at a subsidised rate of MK500 (US$4) per patient per month.

But the country's ARV rollout programme has been plagued by delays of *'up to eight months'* in supplying the drugs, which had led to people in urgent need of treatment being forced to wait before accessing the life-prolonging medication. ARV shortages in the public health system meant that people, who had reached the stage of AIDS, were told to *'go home and wait'*. The fear was that if the procurement system did not improve, the problem of drug shortages and delays, in a country with an HIV prevalence rate of 14.4% and 150,000 people in need of treatment, would not be solved.

Currently, Malawi is purchasing ARVs with a US$20 million grant from the Global Fund to fight TB and HIV/AIDS, which stipulates that the United Nations Children's Fund (UNICEF) should be used to procure the medication. Nevertheless, a large consignment of drugs was expected by May 2005, and all 59 treatment sites would begin providing ARVs from June 2005 onwards. About 19,000 people are accessing the medication through the public sector, as well as treatment initiatives by aid agencies like Medicines Sans Frontieres (MSF). In terms of the World Health Organisation's 'three by five' plan, to provide treatment to three million people in the developing world by the end of 2005, Malawi should have 80,000 people on ARV therapy by the end of 2005. This target was virtually impossible to achieve, partly, because the medication had arrived later than planned, but also as a result of crippling staff shortages in the health sector.

Through the HIV and AIDS treatment initiatives, it is pleasing to note that as of 30th November 2005, about 32,000 patients were started on ART in 60 health facilities and with a constant supply of drugs, the number of Malawians accessing, and keeping on, treatment should continue to grow steadily. To show goodwill, the Malawi Government, through the National AIDS Commission, is urging all members of the general public to go for HIV testing, and, if needed, for assessment at the nearest hospital to determine whether or not ART needs to be started. In this regard, a total of 23 private and company owned clinics have been accredited and certified by the Malawi Government, in collaboration with the Malawi Business Coalition Against HIV/AIDS (MBCA), to start providing ARVs at a cost of MK500.00 (the equivalent of US$4.00) per month. Other services, such as consultations, procedures, laboratory services, drugs other than ARVs, are being charged according to the prevailing prices in various clinics. The clinics have limited numbers of new patients starting on ARVs each month.

The *'light'*, being referred to in the beginning of article, refers to the arrival of a consignment of anti-retroviral (ARV) drugs for the private sector. With this consignment, and in line with the Global Fund principle of promoting public/private partnership,

30 private sector health facilities started providing anti-retroviral (ARV) drugs at a subsidised rate of MK500 (close to US$4.00) per month. This private sector anti-retroviral therapy (ART) programme is being coordinated by the Malawi Business Coalition Against HIV/AIDS (MBCA).

CHALLENGES MALAWI IS FACING IN THE FIGHT AGAINST THE HIV AND AIDS PANDEMIC

That Malawi is one of the countries hit hard by the HIV and AIDS pandemic is not news. The level of awareness amongst the people is high. Many people know that sexual intercourse continues to be the number one mode of HIV transmission. But the awareness is not translating into noticeable sexual behaviour change. Some people in Malawi are still engaging in unprotected sex with multiple partners. Some HIV infected women are intentionally giving birth, even when they are not on Nevirapine, the drug that reduces the risk of mother-to-child transmission. Sexually transmitted diseases (STDs) and infections (STIs) are also still a matter of concern in the Malawi health sector.

According to a recent survey by the National AIDS Commission, people are not changing their sexual behaviour. The findings show that knowledge levels are very good, but behaviour change is still a challenge. According to this survey, the youth, aged between 15 and 24 years, particularly girls, are at great risk of contracting HIV, because of intergenerational sex, popularly known as *'zidyamakanda'* in our native language.

The challenge is, therefore, placed on NGOs, the Faith-based Organisations (FBOs) and the community-based organisations (CBOs) to come up with more innovative strategies and creative interventions to influence speedy sexual behaviour change. Only then would the country be able to arrest the spread of HIV, currently at 14.4% per annum.

Another challenge is the current boom of *'fake AIDS drugs'* in Malawi, spearheaded by Malawian herbalists and other foreign clinics. Many people living with HIV and AIDS are forced to rely on illicit drugs, in a bid to treat various opportunistic illnesses, ease suffering, and prolong their lives. It has been noted that some of the *'fake drugs',* flooding the country's parallel market, have potentially disastrous after-effects. This is due to lack of recognised cheap drugs in public hospitals, clinics and health centers, coupled with their exorbitant costs in the marketplace. Attempts, by authorities, to crack down on the illegal sales of such drugs have, over the years, proven unsuccessful.

Towards the end of 2004, a drug called *'Chambe',* discovered by a Malawian herbalist, George Liunde Kumbuyo, who was then based in East London, South Africa, claimed to be doing well and working wonders on patients infected by AIDS. Malawi health officials strongly dispute Kumbuyo's claims that *'Chambe'* is a cure for AIDS. Another drug, which is also claimed to be responding to AIDS, and selling like *'hot cakes'* in some Chinese clinics, is Conthy Capsule. Conthy is a traditional Chinese medicine, developed by the Beijing Jinjiang Xini Pharmaceutical Company. A packet of 20 Conthy Capsules cost up to K5,000 (the equivalent of US$4.00). This is not a registered drug in Malawi.

There is a host of other drugs, such as Rifampicin, IHN, Maridiana, African potato from Zambia, and Chisupe claimed to be curing AIDS, but this is just a myth! Instead, all AIDS infected people in Malawi have been advised and encouraged to seek ARVs from public clinics, free of charge, or from private and selected privately owned clinics, for affordable subsidised ARVs.

Lastly, another devastating challenge Malawi is facing in its fight against HIV and AIDS are the cultural practices that

exacerbate the spread of this pandemic. In brief, these include:

- Polygamy – a practice, by which a man married more than one wife, with a high risk of HIV transmission;
- 'Fisi' (Hyena) – this is a situation where, when it is realised that the wife is failing to conceive, due to the husband's impotence, the relatives of the husband encourage the woman to engage in sex with her husband's brother. This practice risks the right to health and spreads HIV;
- Wife inheritance – traditional chiefs and elders still take part in forcing women into *'Chokolo'* inheritance;
- Replacement of a deceased – this is a practice, by which a bereaved husband marries a younger sister, or niece, of the deceased wife;
- Bonus wife – the girl is in most cases treated as an object, when the contract of marriage is negotiated. Girls, as young as 11 years, could be married off;
- 'Kupimbira/Kuhara' – this is a practice where parents marry off their daughters, mostly in payment of debt, or for any other purposes. Girls, as young as 11 years, could be married off;
- Marriage by proxy – many young men travel to seek employment outside the country. In their absence, the husband's brothers are asked, by elders, to look after their sister-in-law, including engaging in conjugal relationships with the wives, and, thereby, spreading the pandemic;
- Wedding dances – there is a particular dance, called '*Ntongo'*, in some parts of the country, which takes place at the vigil on the night of the wedding, and promotes promiscuity and, hence, the spread of STIs, including HIV.

WAY FORWARD

Malawi acknowledges the fact that over and above the knowledge about HIV and AIDS, prevention methods, and how poverty contributes to the scourge, a unique way of combating the pandemic is by empowering the youth, economically, as future leaders. Although the current rhetoric is *'prevention is better than cure',* nobody can change behaviour if her or his living standards remain poor. Women and girls are amongst the vulnerable groups, who get into sexual encounters to earn a living. Hence, encouraging this vulnerable group to engage in some small-scale income generating activities would be the most effective way of eradicating poverty amongst girls and boys.

Focusing on imparting income generation skills, and linking vulnerable people to money lending institutions to fight poverty, that has been identified as the major cause of the HIV and AIDS pandemic, is the role HIV and AIDS activists can play, in addition to advocating for preventive measures. Sustainable livelihood is the only effective weapon against HIV and AIDS.

As cultural and traditional practices continue to influence the Malawian society, and, thereby, increase the spread of HIV and other sexually transmitted diseases, advocacy against such practices, needs to be intensified in Malawi. The youth, who are the future of this country, are patronising such cultural practices in multitudes, and, hence there is the need for on-going advocacy interventions.

The activists could also keep on reminding government on its commitment on the implementation of the UNGASS Declaration of Commitment on HIV/AIDS, and, if it back-tracks, to hold government accountable!

FOOTNOTES:
1. United Nations General Asembly Special Session of HIV/AIDS (UNGASS).

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making a point

Kabir Bavikatte

HIV and AIDS amongst conflict-affected and displaced populations

INTRODUCTION

The repercussions of armed conflicts are complex and involve not just widespread physical and sexual violence, but also large scale population displacement, food and medical shortages. Wars can increase the spread of sexually transmitted infections (STIs) and facilitate HIV transmission through sexual routes, injection drug use (IDU), contaminated blood transfusions and occupational injuries. Armed conflicts can influence HIV epidemic dynamics in surrounding countries and beyond, both directly by affecting HIV transmission itself and indirectly through re-allocation of health-related public funds toward security and defence measures. Poverty, powerlessness and social instability, all of which facilitate HIV transmission, are extremely heightened in conflict situations.[1]

DIRECT EFFECTS OF CONFLICT ON THE SPREAD OF HIV

There are diverse ways in which HIV spreads in conflict situations. These routes can be both direct, such as the impact of conflict on sexual transmission and drug use and indirect, such as break down of health infrastructure and redirecting of public health spending into defence budgets.

Sexual transmission of HIV in conflict situations

Sexual transmission of HIV in conflict situations occurs through a) massive displacement due to conflict and, thereby, groups that have a high incidence of HIV infection coming into contact with groups with low incidence and knowledge about HIV; b) rape or sexual abuse of women and children; c) economic necessity forcing women to engage in sex to survive; and d) high HIV prevalence amongst military personnel and the creation of economies based on commercial sex for soldiers separated from their families around military bases.

Conflict induced displacement

Conflict creates massive displacement of people who flee from their homes to escape violence and starvation. In such cases, there is a likelihood of rural populations, where there are low HIV infection levels and knowledge coming into contact with urban populations with high HIV infection levels. A case in point is that of rural Sudanese refugees in Uganda.[2]

In addition to this, displacement tends to disrupt social networks and institutions that normally protect and support people. Displacement also places people in chaotic circumstances in which access to condoms and other prevention tools may be scarce.[3]

By 1987, HIV had spread from northern areas of Angola to central and southern regions, accompanying war-induced population displacement.[4] In Rwanda, by 1998, a decade of ethnic war, upheaval and mass movements of refugees escaping violence had fanned an escalating HIV epidemic, which spread from cities, such as Kigali, to the countryside.[5]

Rape and sexual abuse

Refugees, especially women and children, who usually have limited access to resources, are very vulnerable to sexual exploitation by people with food or money, and to rape by people with weapons. Rape, is often used both by soldiers and militants as an instrument of power to control, terrorise and displace populations.[6] HIV risk increases, if there are multiple perpetrators, or if women are held in captivity for long periods of time.[7] In the context of an emerging HIV epidemic, widespread sexual violence can have devastating health effects.

Rape as a *'weapon of war':* A 2001 study found 9% of women displaced by armed conflict had been sexually assaulted (UNAIDS/UNHCR, 2003). In a variety of recent conflicts, including Bosnia-Herzegovina, Democratic Republic of Congo, Liberia and Rwanda, combatants used rape as a weapon of war. A study in Rwanda revealed 17% of women, who had been raped, tested HIV positive, compared with 11% of women, who had not been raped (UNAIDS/UNHCR, 2003). In some conflicts, young men and boys have also been targets of rape.

During Liberia's civil war, nearly half of civilian women and girls were estimated to have been physically or sexually abused in the first five years of fighting.[8] Risk can continue in refugee camps. In Liberia, for instance, the setting up of women's shelters on the fringes of the camps, made women more susceptible to sexual violence from military personnel, police and male refugees.[9]

There is a high risk of HIV infection of women and children raped by military and paramilitary personnel. Even in peace times, the STI rate is two to five times higher for military personnel, than for civilians.[10] A small study in Angola showed that HIV rates were four to five times higher amongst members of the military, than amongst the general urban population.[11] Studies have shown that the geographical pattern of the spread of AIDS in Uganda, during the first six years of the post-Amin civil war, can be linked to the placement of the Ugandan National Liberation Army.[12]

Women's risk of contracting HIV, as a result of sexual violence, also increases when there are multiple perpetrators, or when women are held by military personnel for prolonged periods of time for sexual purposes, as has been reported in recent emergency situations.[13]

Survival sex

Women and girls, who are affected by conflict, are usually in such desperate circumstances that they may engage in transactional or 'survival sex' with men, who have food or money, to feed themselves and their children.[14] The presence of large numbers of soldiers with food and money, and the extreme conditions of refugee women and girls, usually creates a sex industry around military bases, which increase the risk of HIV infection for sex workers and uniformed service personnel.

Women and children make up approximately 80 per cent of the 40 to 50 million refugees and internally displaced persons worldwide. Men often leave, or are separated from their families for military reasons, or in their search for employment in the cities, or may be targeted by soldiers or militants, or be killed, or taken prisoner. This creates female-headed households that tend to be financially desperate, due to limited education, low earning ability, when far from their home area, and with few real alternatives to trading sex for money.

There is a high likelihood of the death of, or the loss of contact with, a spouse in conflict situations. This sometimes leads men and women to seek new partners in situations that may not be supportive of long-term relationships. Conflict situations can also create risky sexual behaviour and substance abuse amongst

people, whose future is uncertain and who are trying to cope with the trauma of violence and displacement. In Sudanese refugee camps in northern Uganda in 1996, beer brewing and selling were common activities for young refugee women, most of who were separated or widowed due to war. Unprotected sex with multiple partners, while under the influence of alcohol, was common.[15]

Military

Estimates suggest that sexually transmitted infections amongst soldiers could be at least twice as high as in the general population. In some countries where HIV has been present for more than 10 years, armed forces report infection rates of 50-60%. Even in peaceful Botswana, one in three members of the military has tested HIV positive.[16]

High HIV infection rates amongst El Salvador soldiers were attributed to high levels of sexual risk behaviour associated with the 12 year civil war and numerous prostitution centres surrounding military posts.[17] Among surveyed peacekeepers and soldiers from the national army, only 23% could cite at least three HIV-transmission routes; 38% reported not being worried about AIDS; and only 39% had used a condom during their last sexual encounter.[18] In Sierra Leone, sexual contacts with foreign soldiers, from countries with high HIV levels, rapidly increased the rates of STI and HIV.[19]

Transmission of HIV in conflict situations through injecting drug use

Wars and conflict can increase injecting drug use (IDU) by disrupting traditional supply routes of drugs that can be smoked, sniffed or orally consumed. At the same time, conflict can also create shortages of sterile injecting equipment. Afghanistan, which provided 75% of the world's heroin supply in 1999, is a case in point. After the US invasion of Afghanistan, there were huge disruptions in opium supply and prices. In Taliban controlled areas, opium prices increased ten times, but in other areas they dropped from 1200 USD/kg to 176 USD/kg.[20]

Increasing prices force drug users to use other methods of consumption to reach the highs they are used to, with small amounts of the drug. The most cost efficient method then becomes injecting. Military and police pressure on the Afghan-Pakistan border, during the US led invasion of Afghanistan, disrupted heroin supplies and resulted in decreased heroin quality in Quetta and Lahore. Many heroin users, who previously inhaled heroin fumes, switched to injecting synthetic drugs, particularly ones which were cheaply and widely available from chemists.[21]

INDIRECT EFFECTS OF CONFLICT ON HIV TRANSMISSION

Breakdown or lack of health infrastructure

Conflict in many cases diverts funds from health spending to defence. Conflicts also create huge demands on the health infrastructure, while at the same time contributing to its collapse. Within this context, low awareness of HIV/STIs, lack of access to HIV/STI prevention supplies; fluctuating availability and prices of non-injectable drugs; and non-existent or weakened prevention programmes combine to create conditions ripe for the spread of HIV.

Reduced public health spending

Global responses to the HIV and AIDS epidemic may be negatively affected by wars around the world. Countries affected by conflict usually do not prepare successful funding proposals to bilateral, multilateral, private sector donors or the new Global Fund on AIDS, Tuberculosis and Malaria (GFATM). The GFATM fund depends on contributions from public and private sources that are not forthcoming with the money at a time when much of their resources are, for instance, diverted to the so-called *'war on terrorism'*. The Commission on Macroeconomics and Health,

recommended that the GFATM should fund around US $8 billion per year by 2007, and US $12 billion per year by 2015 for AIDS alone[22], but after September 11th in the first round of proposals to the GFATM, countries asked for US $1.2 billion, but only US $700 million was available.[23] This decreased contribution will drastically reduce HIV prevention; increase treatment budgets; increase the economic and social crises in developing countries; and result in significant security implications for the industrialised world.[24]

Risks related to healthcare

The risk of HIV transmission can also occur from poorly sterilised equipment in conflict situations, if organisations providing healthcare do not have adequate infrastructure. There is also an increased risk of accidental HIV transmission, and other blood-borne infections, between patients and/or healthcare workers in conditions of enormous stress and collapsing healthcare systems. These risks are heightened in mass immunisation campaigns, overuse of intramuscular injections and intravenous infusions, incision procedures when supplies are inadequate, unsafe sterilisation practices, and poorly trained and supervised staff. Healthcare workers may also be at increased risk of HIV infection, due to needle-stick injuries, or exposure to open cuts, blood and body fluids of an infected patient, especially under chaotic emergency conditions. Although, blood screening has reduced the risk through transfusion in most parts of the world, HIV is still transmitted through transfusions, even under stable conditions.

In a study in Kenya, the risk of HIV infection from a blood transfusion was estimated at one in 50, a statistic 10,000 times higher, than figures in industrialised countries, such as the United States or France. Contributing factors included poor record systems, breaks in the cold chain while transporting test kits, collection of blood from family members when rapid tests are not available, and the assumption that a mother and her child have the same HIV infection status.[25]

HIV risk from blood transfusion tends to be high in conflict situations since a number of conflict-related injuries require transfusion. This is more so, if there has been a breakdown of the health infrastructure in conflict affected areas.

CONCLUSION: PREVENTIVE MEASURES

Preventive measures in conflict situations tend to be limited, but they can nevertheless be very effective in combating the scale of HIV infection. The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the UN High Commission for Refugees (UNHCR) have developed a minimal initial services package (MISP) that can be used in emergency situations. The MISP includes basic information on HIV and AIDS, condom access, safe blood transfusion, and materials to implement universal precautions in refugee camps.[26]

There needs to be supplies of sterile needles and infusion kits, and the implementation of safe sterilisation practices is required to prevent infection of patients through re-use of contaminated equipment. Adequate supplies of gloves, gowns, eye protection and other materials are essential for health workers to protect themselves from being infected. It is also important to ensure easy access to condoms and the availability of basic HIV information in a culturally appropriate language.

The possibility of rape and sexual abuse can be diminished by ensuring adequate protection for women and unaccompanied minors in refugee camps. Attempts have to be made to reduce the need to engage in survival sex, by providing opportunities and skills to refugees and conflict affected people to be able to earn an income. People, who choose to remain in sex work, need to be given access to condoms, be protected,

and empowered to demand condom use from their customers.

Needle exchange programmes in countries with disrupted drug routes, should be initiated and/or expanded to address increased drug use. This would be a significant way to reduce the spread of HIV in India, Pakistan, Bangladesh, China, Iran, Tajikistan, Uzbekistan, Turkmenistan and other countries in the region as a result of the invasion of Afghanistan.[27]

Decision makers should be informed that providing sterile needles and syringes has not been shown to increase drug use, or provoke initiation of drug injecting. Fluctuating drug supplies and prices should be responded to by drug substitution programmes, using methadone and other medications to prevent drug users from moving towards IDU.[28]

Despite the aforementioned preventive measures not being widespread, it is encouraging to note that there is a growing articulation of these measures in international forums addressing concerns of refugees and displaced populations. Nevertheless, we still have a considerable way to go before any of these measures become institutionalised responses to any conflict situation. That requires a greater mobilisation, locally and internationally, by civil society organisations working on HIV and AIDS and conflict affected populations.

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Khabzela:
The life and times of a South African[1]

Liz McGregor

A common question I've been asked since my book, *'Khabzela: The Life and Times of a South African',* was published on 12 September 2005, the day he would have turned 37 had he lived, was how I came to write it. The answer is that, although I am a South African and worked as a politically engaged journalist here for several years, I left the country in 1985 and returned at the end of 2002. In 2003, I was working as a freelance journalist for various publications in South Africa and abroad and one of the magazines I wrote for was a New York-based magazine for people living with HIV, called *POZ*. They asked me for an interview with a black celebrity living with HIV: a very rare commodity in 2003. Then Fana Khaba aka Khabzela, the hottest DJ on the top youth radio station, Yfm, announced on air he was positive. I interviewed him and became increasingly compelled, partly by his own desperate struggle for life, but also by his life story, which seemed to have encompassed many of the major events that had transformed the country during my long absence: the final convulsive years of the liberation struggle, the arrival of a democratic government, the redemption of the so-called *'lost generation'*, whose education and employment prospects had been blighted by Apartheid. And the arrival of HIV and AIDS.

Khabzela was already very ill by the time I met him. He had dementia and a lot of what he told me didn't make much sense. I had three long sessions with him but mostly, my picture of his life was gleaned from interviews with his family, friends and colleagues. I learnt a lot from my various researches.

The most surprising thing for me was the discovery that ambivalence about HIV and AIDS was not confined to the president and his minister of health. While I was in London, and after returning to South Africa, my understanding was that if only these two would get over their denialism, and make ARVs universally accessible, the pandemic could be turned around. My journey through Khabzela's life taught me that distrust of ARVs and ambivalence about western medicine, in general, is widespread. Yfm offered to pay for Khabzela's treatment; thus, access was not an issue. Nor was education, since he frequently preached the safe sex message on radio. He was an independent-minded, irreverent man and it was unlikely he would have slavishly followed the views of the political leaders. Yet, he threw away his ARVs after two weeks and resorted to a range of traditional healing remedies, as well as immune boosters touted as miracle cures. When he first became ill, he believed he had been bewitched by a rival DJ, who wanted his job. He went to a traditional healer to rid himself of the foreign entity (variously described to me as a *'lwazi'* or an *'isidliso'*), which had been infiltrated into his body and was consuming him from the inside.

I discovered that his views were common amongst his peers, all modern, urban, relatively highly functioning young people.

Khabzela died, because he refused to take the only medication that would have given him a chance of suppressing the HI virus, anti-retrovirals. Why wouldn't he take them? I thought the answer came from his life experiences: everything that had led to the making of Fana Khaba in January 2004, the date of his death – conspired against his capacity to make the adjustments necessary to save his life.

Primary amongst these was his notion of masculinity: this seemed to me to be a fragile construct. His father, a drunken wife-beater, died when Fana was four and was despised by his family. Fana was brought up in a female-dominated household by older sisters and a very strong and capable mother. Growing up, his main male role models were the gangsters: they appeared to have broken through the glass ceiling created by Apartheid for young black men; they had plenty of

Khabzela: The life and times of a South African *cont.*

money, expensive cars and clothes, and beautiful women. Their lifestyle was not sustainable, they lived fast and died young, but it was the lifestyle Khabzela emulated once he became rich and famous.

It came with a price: to call himself a man, a successful, admired man, unlike his father - he had to support his entire extended family, plus his five children and their five mothers; and all the girlfriends required presents. The pressure to perform sexually was intense; he was hugely promiscuous, sleeping with every groupie, who offered herself to him.

In order to deal properly with his illness, he needed to give up control, to submit to the ministrations and directions of doctors and carers. This induced panic and terror in him. He could not find the inner resources to make the necessary transformation. He felt emasculated, because he was no longer on air at Yfm, the source of much of his power and prestige. When the queue of miracle peddlers started knocking at his door, hoping to achieve fame and fortune on the back of the Khabzela brand, his power of patronage appeared to have returned and he entertained them all, including Tine van der Maas, the Dutchwoman sent personally by the minister of health to nurse him, although Fana, at this point, November 2004, was too weak to make his own choices. He had dementia, kidney failure, peripheral neuropathy, large and infected bedsores, chronic bloody diarrhoea and a chest infection. Yet, van der Maas claimed she could cure him with her diet and a vitamin preparation called *'Africa's Solution*'. Later, I discovered she expected to receive R1 from every bottle of *'Africa's Solution*' she sold, a claim she denies, professing to promote it only because of its effectiveness.

The problem of van der Maas and her ilk, and the political atmosphere, which allows such characters to flourish, has already been much explored. But one aspect that seemed to me to need addressing also affected Fana: the dementia that frequently accompanies the latter stages of AIDS. Patients with dementia are often not able to make rational decisions for themselves. Who then takes control? What is the legal position?

Another major reason for Fana's rejection of ARVs was his faith in traditional healing systems. If this is indeed a common response, and I had the impression it is, surely it must impact on public health policies. If someone believes they have been bewitched, it fundamentally alters their understanding of what ails them, and prevention and treatment messaging must take that into account. All the evidence is that current messaging is not working; infections continue to rise despite the millions of Rands poured into education and treatment. An attachment to traditional healing could help explain that.

The safe sex injunction becomes irrelevant, if you don't believe your malady is caused by a virus transmitted through sexual intercourse. If the first port of call is a traditional healer, the latter should be engaged by the medical establishment.

Since the book was published, I've done several radio interviews and have been struck by the number of black callers who have accused me of undermining African traditional healing by insisting on ARVs as the only option for Fana. These callers always bring up the question of choice. AIDS patients need, they say, to be able to choose from the range of remedies on offer.

So, to sum up, the situation on the ground is a great deal more complex, than it would appear, and denialism is not confined to the president and his minister of health.

FOOTNOTE:

1. The book *'Khabzela: The life and times of a South African'* is written by Liz McGregor, published by Jacana Media, and available in all good bookstores.

This publication has been made possible through the assistance of the Joint Oxfam HIV/AIDS Programme (JOHAP) managed by Oxfam Australia

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