SOUTH AFRICA HIV Leadership through Accountability

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HUMAN RIGHTS COUNT!
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Eastern Cape Assessment 2011

NAPWA SOUTH AFRICA

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

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Acronyms

ANC	Antenatal care
ARV	Antiretroviral
CSO	Civil Society Organisation
DfID	UK Department for International Development
ECAC	Eastern Cape AIDS Council
GNP+	Global Network of People Living with HIV
HSRC	Human Science Research Council
LTA	HIV Leadership through Accountability Programme
NAPWA	National Association of People Living with HIV and AIDS
NGO	Non- governmental organisation
PLHIV	People Living with HIV
SAHRC	South African Human Rights Commission
UNDHR	Universal Declaration of Human Rights
WAC	World AIDS Campaign

Acknowledgements

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NAPWA is immensely grateful to the UK Department for International Development (DfID) Governance and Transparency Fund, which made the *Human Rights Count!* study in Eastern Cape Province, South Africa possible.

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Contents

Executive Summary

This report is an account of the *Human Rights Count!* study carried out in the Eastern Cape Province by the National Association of People Living with HIV and AIDS (NAPWA) with technical support from the Global Network of People Living with HIV (GNP+) and the Eastern Cape AIDS Council (ECAC). Fifteen members from NAPWA who reside in the study area were chosen to do the data collection. They collected data from a total of 174 respondents.

Human rights and HIV in South Africa

South African society continues to be ravaged by the scourge of the HIV and AIDS pandemic. The country continues to have the highest number of people who are infected by HIV in the world, with an estimated 5.7 million people living with HIV. The OR Tambo District was chosen for the *Human Rights Count!* study because it has the second highest HIV prevalence in the Eastern Cape Province, and there have been high-profile cases of HIV-related human rights violations.

Despite strong legal frameworks protecting the rights of all people in South Africa, effective strategies to address the human rights violations suffered by people living with HIV (PLHIV) are yet to be developed. PLHIV are still subject to serious forms of stigma and discrimination. They are at risk of losing their jobs or not being offered jobs, being ostracised by their families, friends, workmates and communities, and suffering various forms of ill treatment including discrimination, harassment and physical abuse.

Study findings

Most respondents were female, and three quarters knew they were HIV-positive. Half the respondents had attained secondary school education, and only a small proportion having no formal education. At the time they experienced a human rights violation, the majority of respondents were unemployed.

The most commonly reported human rights violations related to the right to privacy, freedom from torture, access to health, the right to marry and found a family, and the right to work. A significant proportion of respondents mentioned other types of rights violations. Physical abuse, ranging from being raped, beaten, stabbed or even murdered, was the most commonly experienced type of abuse. Most of the victims of physical violence were abused by family members like parents, spouses or their own children. In fact, human rights violations in general were most commonly committed by immediate family members. The next largest groups violating PLHIV rights were reported to be community members and health care providers. Respondents described several cases where health care workers refused to give treatment by not giving out the necessary medication or by turning clients away.

The violations had various negative impacts on the respondents; they frequently mentioned experiencing psychological, social, physical, and — to a lesser extent — economic impacts. Less than a third of the respondents reported the violations to the relevant state authorities, either because they did not know that they could report, they did not know who to report to, they were afraid, or they did not think it would make a difference. While some people said that the perpetrators were arrested, very little concrete actions were taken in most cases. When asked whether they thought there were government policies or laws to prevent violations against PLHIV, over half the respondents didn't know.

Conclusion

Human rights violations are happening every day to individuals in households and communities. *Human Rights Count!* is a way of documenting such gross maltreatment of people affected and infected with HIV. The poor, illiterate, uneducated and unemployed — mostly women — bear the brunt of human rights violations which have been exacerbated by their HIV status. Families and communities which are supposed to offer care and support as well as mitigate the negative circumstances facing PLHIV very often seem to be the perpetrators of human rights violations, as has been shown by the results of this study. On the other hand, while advocacy is being done to ensure equity and equality in the provision of health services, people living with HIV still experience rights violations when they access health services. The supporting structures such as the police services do respond to the plight of PLHIV regarding human rights violations, but this needs to be optimised. More work has to be done at all levels to ensure that the rights of PLHIV are safeguarded.

Recommendations

- Support groups are central to the provision of care and support, since communities are a place full of gross human rights violations. NAPWA needs to extend their support into all communities to service their membership.
- NAPWA together with other civil society organizations should work closely together to challenge existing societal attitudes and prevailing cultural norms. This work should include training their membership and communities on human rights issues to minimise cases of human rights violations.
- The documentation of human rights violations should form the core of what NAPWA does. This work should become an ongoing program extended to all the areas of the Province. The documentation of such human rights violations will assist NAPWA in giving policy advice to government using an evidence-based approach.

- An integrated community awareness program should be developed at the national level to address issues of stigma and discrimination. Communities need to be educated on the existence of legal services that they can access if faced with stigma and discrimination.
- The conveners of support groups should be adequately and comprehensively trained in human and legal rights for PLHIV.
- The government needs to ensure the translation of human rights legislation and policies into practice, and also to provide an inclusive platform for policy development that ensures input from PLHIV. The government should ensure the implementation of the Greater Involvement of People living with AIDS (GIPA) principle in all HIV-related strategies.
- A clear human rights framework has to be developed and human rights should be mainstreamed into all HIV programmes. An accessible justice and legal system needs to be established and have a good turnaround time for dealing with cases reported to relevant authorities, especially those cases involving human rights violations against PLHIV.
- The victim empowerment programme needs to be extended to reach those whose rights have been violated because of their HIV status.
- There should be adequate resource allocation for the implementation of advocacy programmes to de-stigmatise HIV, raise awareness, and engage in community dialogues.

South Africa

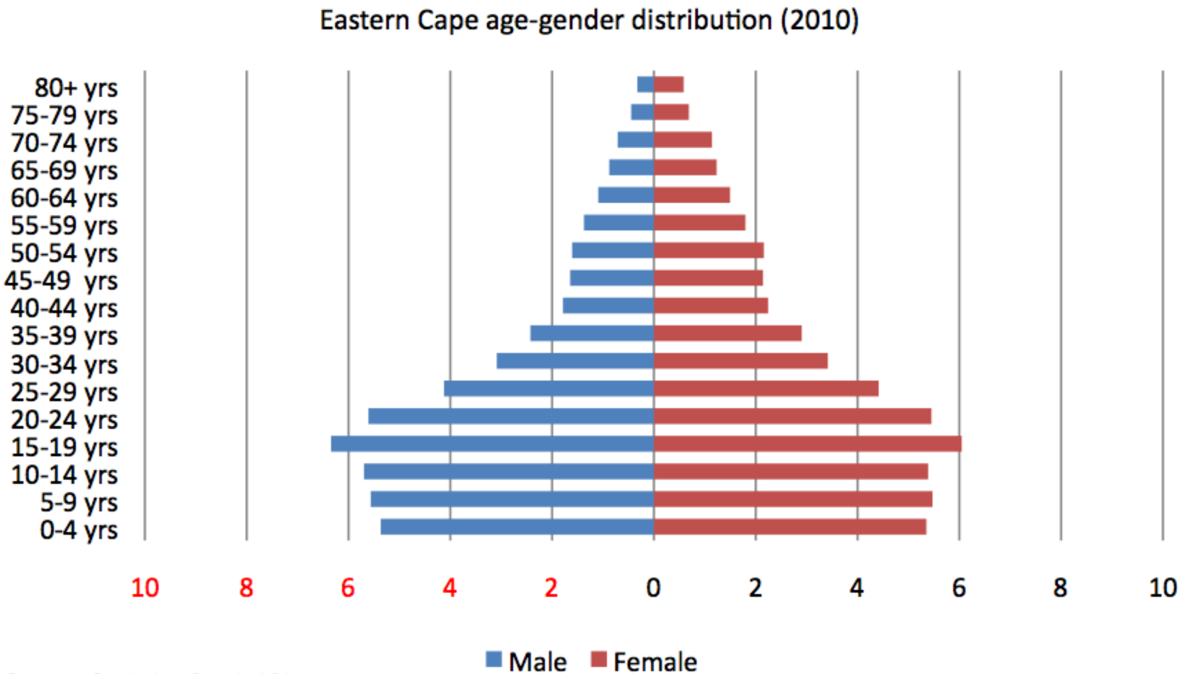
Chapter 01 – Country Profile

HIV/AIDS Situation in Eastern Cape

South African society continues to be ravaged by the scourge of the HIV and AIDS pandemic, together with its related diseases, especially the surging tuberculosis/HIV co-infection rate. There have been signs of a steady decline in the HIV infection rate but the country continues to have the highest number of people who are infected by HIV in the world, with an estimated 5.7 million people living with HIV.[1]

The Eastern Cape is the second largest province in South Africa, covering 13.8% of South Africa with a total land area of 169 056 km2. It is the third most populous province in South Africa (13.5%) with approximately 6.7 million people, 87.6% of whom are African, 7.5% Coloured, 4.7% White and 0.3% Asian. It is the poorest province in South Africa. Figure 1 below shows the distribution of the population by age and gender.

Figure 1: Eastern Cape population distribution by age and gender



Source: Statistics South Africa

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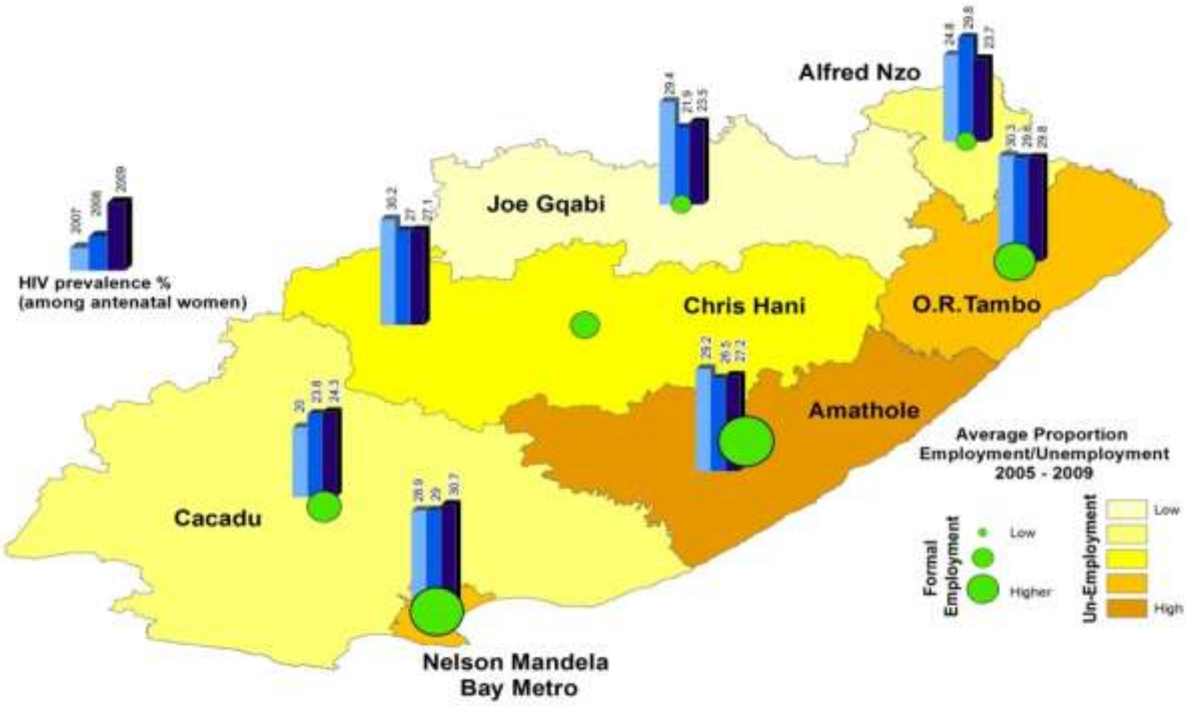
[1] UNAIDS (2008) Epidemiological Fact Sheet on HIV and AIDS, Core Data on epidemiology and response, South Africa

The 2008 national household survey conducted by the Human Sciences Research Council (HSRC) showed an increase in HIV prevalence in the Eastern Cape Province among those who are over two years old, from 6.6% in 2002, to 8.9% in 2005, to 9.0% in 2008.[2] When compared with the other eight provinces, the 2008 data show that the Eastern Cape Province had the fourth lowest HIV prevalence, the lowest prevalence being found in the Western Cape Province (3.8%).

The 2008 National Department of Health's antenatal care (ANC) data was analysed according to province, and the Eastern Cape was again the province with the fourth lowest HIV prevalence (27.6%) with the national average at 29.3% in 2008.[3] When the ANC data collected for the Eastern Cape Province from 2007–2009 were analysed according to the seven districts, the OR Tambo District had the highest HIV prevalence (29.8%) after the Nelson Mandela Metro (30.7%) (Fig. 2).

Figure 2: HIV prevalence of ANC attendees from 2007 – 2009 in the seven local districts found in Eastern Cape



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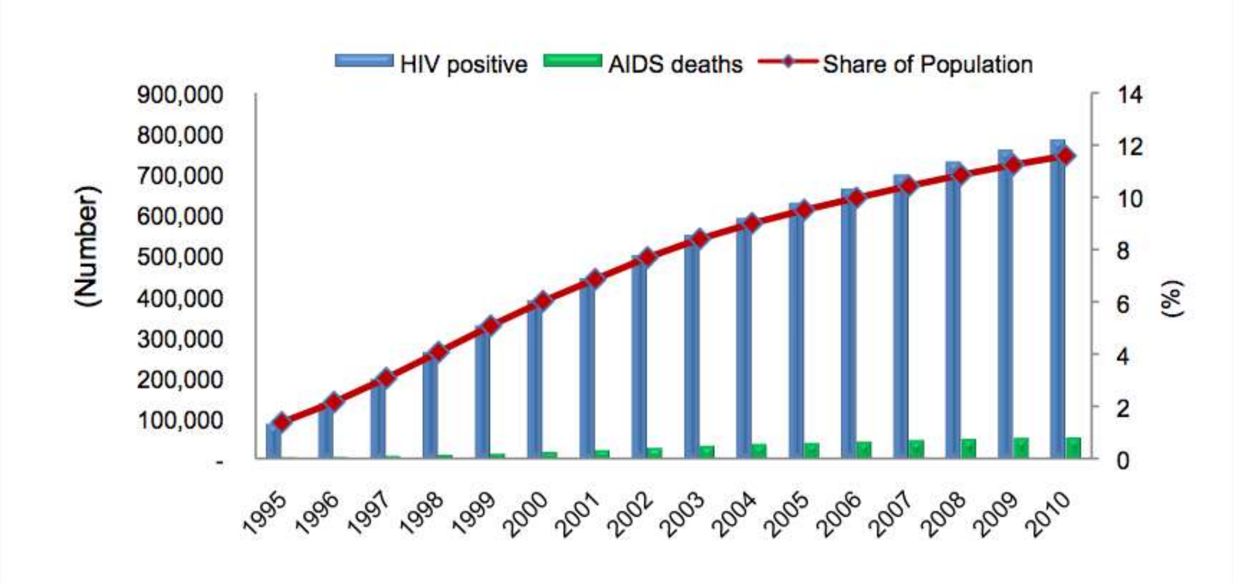
[2] Shisana, O., Rehle, T., Simbayi, L. C., Zuma, K., Jooste, S., Pillay-van-Wyk, V. et al. (2009). *South African national HIV prevalence, incidence, behaviour and communication survey 2008: A turning tide among teenagers*? Cape Town: HSRC Press.

[3] Phaswana-Mafuya, N., Seager, J., Peltzer, K., Jooste, S. & Mkhonto, S. (2010). *Social determinants of HIV in the Eastern Cape*. Cape Town: HSRC.

The number of infected people in proportion to the population has been on the rise since 1995, accounting for 1% of the population in 1995 and 12% in 2010, as shown by the incidence of HIV and AIDS deaths in the province (Fig.3).

Figure 3: Annual incidence of HIV and AIDS deaths in the Eastern Cape



Source: Statistics South Africa

The OR Tambo District was chosen to be the district in which the Human Rights Count! study was conducted because of the following reasons:

- It has the second highest HIV prevalence in the Eastern Cape Province.
- High stigma and discrimination of PLHIV led to a woman, Nokuzola Mfiki, killing herself together with her four young children.[4]
- The HIV counselling and testing campaign was launched in the Ngquza local municipality in the OR Tambo District.

Another factor was the relationship which the National Association of People Living with HIV and AIDS (NAPWA) has built with clinics in the district. NAPWA also has several support groups which provided a great opportunity for the data collectors to interview respondents whose rights were violated at some point.

The OR Tambo is one of the seven districts of the Eastern Cape Province, which is largely rural with very limited productivity whilst very vast in terms of geographical coverage.[5] It is the second largest district in terms of population density as the municipality has an average

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[4] Daily Dispatch 8th August 2009

[5] Department of Economic Development and Provincial Treasury (2010) Eastern Cape Profile and Outlook 2010

of 114 people per square kilometre. It has the highest family size compared with other district municipalities (an average of 5 people per house) and is a district with suboptimal performance in providing its general populace with access to socio-economic services.[6] The OR Tambo District is associated with high levels of HIV-related stigma and discrimination.

Human rights in South Africa

The Universal Declaration of Human Rights (UDHR) approved on 10 December 1948 by the United Nations General Assembly states that “all human beings are born free and equal in dignity and rights...” The South African Human Rights Commission (SAHRC) was inaugurated on 02 October 1995 under the Human Rights Commission Act of 1994 and as provided for by the South African Constitution Act 200 of 1993. The constitution, as the highest law in the country, was adopted to heal the divisions of the past and establish a society based on fundamental human rights listed in the Bill of Rights. The SAHRC has a mandate to develop human rights awareness amongst South African citizens, to make recommendations to improve the respect of human rights, to report to parliament on all matters related to human rights, to investigate all human rights violations, and to seek appropriate relief. The SAHRC works with government, civil society and individuals, both internationally and within the country, to act as a watchdog and a route through which people can access their rights.

However, despite this strong legal framework protecting the rights of all people in South Africa, effective strategies to address the human rights violations suffered by people living with HIV (PLHIV) on account of their HIV-positive status are yet to be developed. PLHIV are still subject to serious forms of stigma and discrimination. They are at risk of losing their jobs or not being offered jobs, being ostracised by their families, friends, workmates and communities, and suffering various forms of ill treatment including discrimination, harassment and physical abuse.

In 1998, in a case that shocked the world, Gugu Dlamini, an AIDS activist, was beaten to death by her neighbours after revealing her HIV-positive status on Zulu television.[7]

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[6] Department of Economic Development and Provincial Treasury (2010) Eastern Cape Profile and Outlook 2010

[7] Reported at, amongst others: http://www.avert.org/media-gallery/image-157-gugu-dlamini-red-ribbon-memorial

Chapter 02 – Methodology

About Human Rights Count!

Human Rights Count! is a programme initiated and led by the Global Network of People Living with HIV (GNP+) to document HIV-related human rights violations against people living with HIV as a result of their HIV positive status. The documentation is based on a PLHIV-driven methodology. The main aim of the programme is to decrease the number of human rights violations against people living with HIV by coordinating evidence-informed advocacy against these violations.

HIV Leadership through Accountability Programme

The HIV Leadership through Accountability programme is collaboration between GNP+, the World AIDS Campaign, national networks of PLHIV and national civil society campaign platforms. The programme is funded by the UK Department for International Development (DfID) and combines specific HIV evidence-gathering tools, national AIDS campaigns and targeted advocacy for Universal Access. The programme will run for five years and involve 11 countries in total.

National networks of PLHIV are leading the effort to document the experiences of people living with HIV and have employed a number of internationally tested and validated tools, aimed at strengthening the evidence in five key areas:

- Stigma and discrimination (The People Living with HIV Stigma Index)
- The level of involvement of people living with HIV (The GIPA Report Card)
- Documenting and analysing current experiences in criminalisation of HIV transmission (The Global Criminalisation Scan)
- Documenting and analysing human rights violations against PLHIV (Human Rights Count!)
- Sexual and Reproductive Health and Rights of PLHIV (Advancing the Sexual and Reproductive Health and Rights of PLHIV: A Guidance Package), supporting PLHIV networks to engage in national processes for the development and/or adaptation of sexual and reproductive health services for key populations

GNP+ developed a process for networks of PLHIV to take the lead in systematically documenting HIV-related human rights violations. A questionnaire to guide data collection was developed after extensive consultations involving PLHIV and human rights organisations among others. In 2009, the project was piloted in Kenya, Nigeria and Zambia by networks of PLHIV working in partnership with human rights organisations.

Human Rights Count! in Eastern Cape

This Human Rights Count! study was conducted amongst PLHIV in four Local Municipalities in the OR Tambo District: King Sabatha Dalindyebo, Nyandeni, Ngquza and Mhlontlo. The interviews were conducted by PLHIV in clinics with working relations with NAPWA. The interviewees were people of all ages, with children below the age of 12 spoken for by their parents/guardians. (The South African Children's Act, no. 35 of 2005 was amended and came into effect on 01 April 2010, lowering the age of majority from 21 to 18 years and allowing 12 year olds to access contraceptives and HIV testing without the parents' consent. This Act stipulates that the child may consent to his/her own medical treatment if he/she is over 12 years old and has sufficient maturity and mental capacity to understand the benefits, risks, social and other implications of the treatment.[8])

Fifteen PLHIV identified from the areas in which data collection was done were trained on how to recruit respondents into the study and also on filling in the questionnaire. The respondents were PLHIV attending support groups, both those affiliated with NAPWA and with other organisations, attached to clinics in the above-mentioned areas. In some cases, members of the support group who knew of a person whose human rights were violated because they are HIV-positive spoke on their behalf, telling their stories. The spoken-for persons were either minors or had passed away. A total of 174 questionnaires were filled in by the 15 trained interviewers. Participation in the study was voluntary, with respondents taking part after the purpose of the study was explained to them and informed consent was asked for and obtained.

Limitations

The main limitation of the study relates to the sampling of the respondents. The experiences documented in this study were primarily collected as self-reported narratives. The sensitivity of the study area may have limited the numbers and diversity of people willing to volunteer their experiences. The final study sample involved a relatively small sample of PLHIV, not fully representative of the actual PLHIV population in the area, hence the results cannot be generalised. Other constraints related to the limited availability of financial and human resources to fully support data collection in the selected study area. These limitations notwithstanding, the study provides sufficiently detailed information to support advocacy for more responsive interventions against HIV-related human rights violations against PLHIV.

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[8] Mahery, P., Proudlock, P. & Jamieson, L. (2010). *A guide to the children's act for health professionals* (Fourth Edition). Cape Town: Children's institute.

Chapter 3 – Findings

Out of the 174 respondents, 39 told stories on behalf of other people: 21 by a family member, 17 by a friend/neighbour, 1 by a social worker.

The ages of the persons whose human rights were violated ranged from 1 to 78 years old with the age ranges shown in Table 1 below. The rate of human rights violations of children under the age of 12 was the same as that of minors between 12 to 17 years old and for youth between 18 – 24 years old (all 4.0%). Most of the respondents whose rights were violated were over 25 years old (82.8%), with the majority taking place against people who were between 25 and 44 years old.

Table 1: Age range of the persons whose story of human rights violation were told by respondents

AGE RANGE OF PERSONS EXPERIENCING HUMAN RIGHTS VIOLATIONS (YEARS)	n	%
1 - 11	7	4.0
12 - 17	7	4.0
18 - 24	7	4.0
25 - 34	57	32.8
35 - 44	53	30.5
45 - 54	22	12.6
55+	12	6.9
Not given	6	3.4
Missing	3	1.7
TOTAL	**174**	**100**

Among people whose gender was indicated, three quarter were female (75.9%). Males represented 23.5% of cases, while 1 person (0.6%) identified as transgendered (Table 2).

Table 2: Gender of respondents

GENDER OF RESPONDENTS	n	%
Female	129	75.9
Male	40	23.5
Transgender	1	0.6
Missing	4	-
TOTAL	**174**	**100**

A significant number of the respondents had some form of education, with only 16.3% having no formal education. Half the respondents (49.7%) had attained secondary school education and 6.5% had post-secondary education.

Table 3: Level of education obtained by the persons whose human rights were violated

HIGHEST LEVEL OF EDUCATION COMPLETED	n	%
No formal education	28	16.3
Primary school	47	27.5
Secondary school	85	49.7
Technical college or Diploma	9	5.3
University degree or other higher qualification	2	1.2
Missing	3	-
TOTAL	**174**	**100**

At the time of the violation, the majority of respondents were unemployed (n=119, 69.6%). Only one fourth of respondents (25.2%) were working, either full-time or part-time, either as employees or self-employed workers (Table 4).

Table 4: Employment status of the respondents at the time of the human rights violation

EMPLOYMENT STATUS AT TIME OF VIOLATION	n	%
Full time (employee)	14	8.2
Part time (employee)	14	8.2
Full time (self employed)	6	3.5
Part time (self employed)	9	5.3
Unpaid caregiver	8	4.7
Unemployed (not working at all)	119	69.6
Not applicable	1	0.6
Missing	3	-
TOTAL	**174**	**100**

At the time of the reported human rights violation, 130 people (76.5%) were HIV-positive, 11 people (6.5%) were HIV-negative, and 29 people (17%) did not know their HIV status (Table 5).

Table 5: HIV status of the respondents at the time of violation of their human rights

HIV STATUS AT TIME OF VIOLATION	n	%
HIV-positive	130	76.5
HIV-negative	11	6.5
Status unknown	29	17
Missing	4	-
TOTAL	**174**	**100**

When asked with which groups the respondents identify, some of them selected more than one group. The most common response was “human rights activist” (48.0%). Being a pregnant woman, a person with disabilities, a member of an indigenous group/tribe, a gay/lesbian or man who has sex with men, an injection drug user or a prisoner were mentioned by a few respondents (Table 6).

Table 6: Groups with which respondents identify

DO YOU IDENTIFY WITH:	**Yes**	**%**
Human rights activists	83	48.0
Gays or lesbians, men who have sex with men	3	1.8
Transgender	1	0.6
Pregnant women	7	4.0
Members of an indigenous group/tribe	6	3.5
People with disabilities	6	3.5
Injecting drug users	4	2.3
Prisoners or ex-prisoners	1	0.6
Migrants	0	0
Refugees or asylum-seekers	0	0
Sex workers or prostitutes	0	0
Other vulnerable minority groups	5	2.9

Reported violations occurred over the span of 20 years, between 1990 and 2010. Looking at the 141 respondents who provided the year in which the violations occurred, we see an increase from two people reporting a violation between 1990-1994 to just over a quarter of the respondents (27.0%) who reported that their violation occurred in 2010 (Table 7).

South Africa

Table 7: Years in which human rights violations were committed

YEAR OF VIOLATIONS	n	%
1990 – 1994	2	1.4
1995 – 1999	3	2.1
2000 – 2004	14	9.9
2005 – 2009	84	59.6
2010	38	27.0

The most commonly reported human rights violations related to the right to privacy, freedom from torture, access to health, the right to marry and found a family, and the right to work. A significant proportion of respondents mentioned other types of rights violations. Respondents could indicate violations in more than one area.

Table 8: Types of human rights that were violated

VIOLATED RIGHTS	n	%
Privacy	34	20.0
Freedom from torture	26	15.0
Access to health	21	12.1
Marry and have children	18	10.3
Work	12	7.0
Education	5	2.9
Not be subjected to detention or exile	5	2.3
Social security	5	3.0
Life, liberty and security	4	2.3
Seek and enjoy asylum	0	0
Other rights	37	21.3

Physical abuse, ranging from being raped, beaten, stabbed or even murdered, was the most commonly experienced type of abuse, reported by respondents (Table 9). Most of the victims of physical violence were abused by family members like parents, spouses or their own children. For example a mother was murdered by her son with a bush knife. All reported rape cases were among women. Women are generally more likely to report a rape than men. In South Africa, about 99% of rape victims are women.

A considerable number of respondents reported being insulted, abandoned or ill-treated by peers as a result of known or perceived HIV status. Most either had their HIV status disclosed or were forced to disclose their status.

In some cases, the victims were discriminated against by their own families, as reported by more than 30 respondents, by being given separate eating utensils, a separate room to sleep in, or even being chased away from home.

Table 9: Some of the types of violations experienced by the respondents

TYPE OF VIOLATION	n	%
Insulted for being HIV-positive	30	17.2
Raped	26	15.0
HIV status disclosed	19	11.0
Beaten up	17	9.8
Abandoned	10	5.7
Chased away from home	8	5.0
Given separate eating utensils	7	4.0
Refused treatment	5	2.8
Forced to disclose HIV status	3	1.7
Murdered	3	1.7
Refused food	3	1.7
Ill-treated by peers at school	2	1.1

Human rights violations were most commonly committed by immediate family members (55.0% of cases), including spouses, boyfriends, parents, children or siblings. The next largest groups violating PLHIV rights were reported to be community members (21.9% of cases) and health care providers (11.2% of cases), including doctors, nurses, lay counsellors and home-based carers (Table 10).

Table 9: Some of the types of violations experienced by the respondents

WHO DID SOMETHING (or failed to do something they should have done)?	n	%
Immediate family member (spouse, boyfriend, parent, child, sibling)	93	55.0
Community member(s)	37	21.9
Health care provider(s)	19	11.2
Employer	5	3.0
Stranger	5	3.0
Kids at school/community	3	1.8
Support group member(s)	2	1.2
Friend	2	1.2
Class teacher	1	0.6
Colleagues	1	0.6
Police services	1	0.6
Not mentioned/Missing	5	-
TOTAL	**174**	**100**

Respondents described several cases where health care workers refused to give treatment by not giving out the necessary medication or by turning clients away. For example a nurse turned away the mother of a sick child, telling her that the child would die in three days' time. Another client was refused antiretroviral drugs (ARVs) and told to go home and wait for her death as her CD4 count was low. One nurse told a respondent that ARVs were for poor people and those who do not have money, and so refused to give her the treatment. In another case, a health care worker refused to open an ARV file for a client; instead the nurse threw the CD4 count file at the client. In one case, it was reported that a prison inmate who was on ARVs passed away because the card he used to collect treatment from the clinic was misplaced by the prison warders.

In some instances, the respondents reported being shouted at and humiliated by health care workers in front of other clients. One victim was slapped by a hospital nurse for wetting his bed. Some health care workers refused to fill in forms so clients could access the disability grant provided to PLHIV with CD4 counts below 200.

In another instance, a nurse forced a respondent to disclose her HIV status to her children. A lay-counsellor told a respondent's husband to go for an HIV test before he dies, thereby indirectly disclosing the wife's HIV status.

Most of the human rights violations happened at home (57.7%) and in the community (24.4%). Many also occurred in health care facilities (10.7%) and in the workplace (3.6%) (Table 11).

Table 11: Some of the places where the violations took place

PLACE WHERE VIOLATION TOOK PLACE	n	%
Home	97	57.7
Community	41	24.4
Health care facility	18	10.7
Work	6	3.6
School	3	1.8
Support group/candlelight memorial	2	1.2
Prison	1	0.6

The majority of the respondents (65.0%) felt that they were treated this way because of their HIV-positive status, while 16.0% were not sure why. When asked about the number of times that the violation happened, most respondents (70.4%) said that it happened more than once, or on and off for a long period of time (Table 12).

Table 12: The number of times human rights violations happened to the PLHIV		
HOW MANY TIMES DID THE EVENT HAPPEN?	**n**	**%**
Only once	49	29.5
More than once	85	51.2
On and off for a long period	32	19.2
Not given/Missing	8	-
TOTAL	**174**	**100**

About one-third of respondents (34.1%) stated that the violation they reported was still happening, while the violations had discontinued in about two-thirds of the cases (65.9%). Some of the reasons cited for discontinuation of the violations were that the victim left home, whether chased away by family or abandoned, the victims passed away, the perpetrators were arrested after the matter was reported to the police, the matter was reported to the village headman, or the perpetrators themselves tested HIV-positive after a while (Table 13).

Table 13: Some of the reasons for discontinuation of the violations		
REASONS FOR DISCONTINUATION OF THE VIOLATIONS	**n**	**%**
Abandoned or left home	29	14.4
Death of the victim	18	10.3
Arrest of the perpetrator	9	5.2
Reported the violation (either to police, headman or parents or friend of the perpetrator)	7	4.0
Perpetrator tested HIV-positive	5	3.0
Support group threatened to take action	4	2.2

The violations had various negative impacts on the respondents; they frequently mentioned experiencing psychological, social, physical, and—to a lesser extent—economic impacts. (Table 14).

Table 14: Types of impact the violations had on the victims

TYPE OF IMPACT THE VIOLATION HAD ON THE VICTIM	n	%
Psychological	80	45.9
Social	45	25.9
Physical	32	18.4
Economic	10	5.8
Other	12	6.9

Less than a third of the respondents reported the violations to the relevant state authorities. Of the respondents who said that they reported the violations to the relevant state authorities, only 73.1% stated to whom they reported the matter. Most of those respondents (78.90%) reported the violations to the South African Police services and the Department of Health (police and nurses). A few people reported the violations to social workers, a paralegal body, a headman or a school governing body (Table 15).

Table 15: Persons to whom the human rights violations were reported by the victims

PERSON(S) TO WHOM VIOLATIONS WERE REPORTED	n	%
Police and nurses	30	78.9
Social workers	3	7.9
Paralegal body	2	5.3
Headman	2	5.3
School governing body	1	2.6

Of the 33 respondents who provided information on what happened as a result of the violations being reported, 14 people (42.4%) said that the perpetrators were arrested, 3 people (9.1%) said a court interdict was issued, and the grandchildren were returned in one case. Otherwise, very little concrete actions were taken (Table 16). In five of the 14 arrests, the perpetrators were either released because of lack of evidence, they never went back to court, or the case is still pending. This is mainly due to the fact that the courts are always packed with outstanding cases, and such cases of rape are sometimes not prioritised, leading to the conclusion that there is a lack of commitment to enforce laws.

Table 16: Consequences of what happened as a result of reporting the violations by the victims

RESULTS OF REPORTING VIOLATIONS	n	%
Arrest was made	14	42.4
Court interdict was issued	3	9.1
Nothing happened	3	9.1
Case is still ongoing	2	6.1
Perpetrator fled away	2	6.1
Case was discussed and solved	1	3.0
Grandchildren returned to victim	1	3.0
Neighbor educated on HIV/AIDS	1	3.0
ARV manager insulted the victim	1	3.0
Case did not go on	1	3.0
Police asked for evidence	1	3.0
Police sent victim to the headman	1	3.0
Police took down a statement	1	3.0
Police asked that they sort it amongst themselves	1	3.0

Apart from reporting to the state authorities, 37 respondents reported the violations to a caregiver in a non-governmental organisation (NGO), to a support group member or to family members (even though in one case where the mother called the victim names). The respondents who did not report the violation to anyone either did not know that they could report, did not know who to report to, were afraid, did not think it would make a difference, were not able to report, or the matter was resolved (Table 17).

Table 17: Reasons given by the victims for not reporting the violations

REASONS FOR NOT REPORTING VIOLATIONS	n	%
Did not know that they could report	43	24.7
Did not know who to report to	32	18.4
Was afraid	25	14.4
Did not think it would make a difference	10	5.8
Not able to	9	5.2
The issue was resolved	4	2.3
Other reasons	8	4.6

When asked whether they thought there were government policies or laws to prevent violations against PLHIV, over half the respondents (58.9%) didn’t know, 17.2% said no, and less than a quarter (23.9%) said yes (Table 18).

Table 18: Respondents' feelings about government policies or laws that prevent violations against PLHIV

DO YOU FEEL THAT THERE ARE POLICIES OR LAWS TO PREVENT VIOLATIONS?	n	%
Yes	39	23.9
No	28	17.2
Do not know	96	58.9
Not given/Missing	11	-
TOTAL	174	100

There were almost equal proportions of male and female perpetrators of human rights violations. A small percentage of the perpetrators (16.5%) committed the violations while carrying out their duties (Table 19).

Table 19: Violation of victims' human rights by the perpetrator while on duty

DID THE VIOLATION OCCUR WHILE THE PERPETRATOR WAS CARRYING OUT THEIR DUTIES?	n	%
Yes	26	16.5
No	95	60.1
Do not know	37	23.4
Not given/Missing	16	-
TOTAL	174	100

Discussion

The respondents provided a wealth of information regarding their responses to human rights violations, including the actions they undertook to get out of those situations and their propositions for the effective management of the rights of people living with HIV. Most of the respondents noted that they are willing to get support for any violations, such as reporting the cases to the police, joining a support group, and getting psycho-social support from social workers and psychologists.

One respondent noted that to get out of the situation they were involved in, they had to "go and stay with a relative and join a support group which has helped me as well by giving me advice and I then realised that I have people to love me or show me that I can still move on with my health/life".

Gender of respondents whose rights were violated

Females represented 74% of the people who reported their rights being violated in this study. This shows that the violation of the rights of women and girl children is still common in communities. This is also evidence that patriarchal society poses a great risk to the violation of the rights of women and thus protecting this vulnerable group should be prioritised. Women have always been vulnerable in society and this has been further exacerbated by HIV/AIDS.

Level of education obtained by the people whose rights were violated

Generally, the OR Tambo district has a very high illiteracy rate coupled with high unemployment. These can impact on an individual's knowledge of their rights and further still, on services that are at their disposal when faced with such violations. The more affluent, educated and employed an individual is, the lesser the violations. These two socio-economic conditions provide an environment conducive for the violation of human rights in OR Tambo. Given such a context, civil society and government need to work together to create conditions that promote human rights, to provide information, education and awareness on human rights issues, and to protect vulnerable groups, including HIV affected and infected individuals.

HIV status of the respondents

Most of the respondents whose rights were violated were HIV-positive and the perpetrators were mostly a close family member (parents, family member, spouse) or community member. One respondent pointed out that: "my sister-in-law said that I was going to kill all her brothers because of my status and it was during a candlelight memorial. I was so depressed". The human rights violations of HIV-negative people were mostly done to those who worked or participated in HIV-related activities. One of the respondents was violated whilst she was implementing a door to door outreach campaign because the organisation that she worked for supports people living with HIV. In other words, she was violated because she was suspected to be HIV-positive. In one of the incidences, a respondent was negative but raped and infected with HIV. The respondent who reported the case noted that "a step-father raped his step-daughter when she was only 14 years old and her mother failed to protect her own child; instead she did not believe her". In this instance, the lack of a support system from the parent makes the child even more vulnerable.

Rights violations in the family context

As some respondents described their experiences, the family is not only a place where their rights are violated because of their HIV status, but also a place where violations can put an individual at risk of HIV. Family members of some of the respondents called them useless, careless, stupid, nobodies and prostitutes who got what they deserved. In two instances, the perpetrators told the victims that the reason they raped them was because they wanted to be healed from AIDS, while in another instance the young men who raped the respondent said that they wanted to know what it feels like to have HIV. One father who raped his daughter said that he cannot plant a cabbage and then let somebody else harvest it. One man said that he wanted to die with his daughter, while another, who had raped his daughter since she was nine years old, continuously told his daughter that she was not his child. A step-father who raped and impregnated his step-daughter said that it was better that he, the step-father, be the one who either infects her with HIV or impregnates her rather than "the dogs out there".

Types of human rights that were violated

While this study was intended to gather evidence and case studies on HIV-related human rights violations, the information that was collected covered an even broader range of violations and abuses based on real or perceived HIV-positive status. In some examples, there was not clear evidence of the link between the violation and an HIV-positive status.

From the cases reported, a significant number of violations/abuse was committed by close family members and friends. One respondent noted that:

> *"The people at my house do not like me and do not want me to play with their children because I am HIV-positive. They say that if their children do not listen, they will end up like me because I did not take care of myself hence I am dying of AIDS. I do not have any more friends and the whole village knows my status without me telling them."*

In another incident, a mother is always insulting her daughter because of her HIV status, noting that it is because she did not listen that she got HIV. The respondent noted that:

> *"I was treated badly in so much that I do not even have friends. I am always indoors, sleeping through fear of not knowing how people will look at me because of the sickness disclosed by my mother."*

Such forms of abuse (insults and disclosure of one's status) were common findings in this study, demonstrating a violation of the right to privacy and even the freedom of association. The result is a huge psychological burden for the one whose rights are violated that can lead to suicidal tendencies or even death. Confidentiality issues are compromised and stigma and labelling continue to escalate.

The violations committed by people closest to the victims pose a great threat to confidentiality, often attribute blame, and show that acceptance and support to the infected is sub-optimal. One respondent noted that:

> *"I was badly beaten by my boyfriend. Saying that I slept with a person with AIDS, he beat me on the road, he hurt me in the head. I was admitted to hospital because he beat me with a stick".*

Another victim was blamed by her mother-in-law for the death of her son. She noted that:

> *"My mother-in-law said that her son, my husband, was killed by AIDS as I am suffering from it and she told everyone in the community. She said that I was not going to get my husband's money and does not even eat the food that I cook because she is afraid of AIDS."*

Communities play a significant role in both driving and averting stigma and discrimination. One respondent describes being attacked by a community member: "He hit me with the back of an axe on my chin, hands and arms. He threw me down and started raping me. I was in the field fetching firewood in daylight". The victim of the violation has since become mentally disturbed and contracted other diseases. The high level of violations occurring within families and the community is a great concern.

Health care services are supposed to provide services to patients regardless of their HIV status in South Africa and these services are guided by the Batho Pele principles. In one of the cases, a respondent reported that "nurses refused to give me assistance because I had been raped". In the health care system in South Africa, a rape victim should get post-exposure prophylaxis to minimise the risk of infection. In another case, the respondent reported that "I was in the clinic to fetch my treatment (ARVs). The nurse shouted in front of the people for me to come and take my AIDS pills. All the people in the clinic looked at me and started laughing". Another related incident was in a clinic setting:

> *"I was sick, and the nurse said to me in the clinic after she looked at my card: 'There is nothing I can do because you have AIDS and there is no cure for AIDS. Go home, you are going to die anyway'. This was said in front of the other people. I went home crying as a result. I developed meningitis and I was admitted to hospital."*

In principle, every health care worker takes a pledge to protect their patients and ensure confidentiality but in this scenario, the health care worker violated this right. Access to health violations (i.e., refusing a patient treatment), ill treatment and disclosure of one's status were common amongst respondents whose rights were violated by a health care worker.

Existence of government policies and their effectiveness

Respondents had mixed feelings and levels of awareness with regards to the existence of government policies and their effectiveness. Most respondents did not know of any laws or policies to protect them from the violations. These study results show that despite the prioritization of human and legal rights in South Africa, there is still too little awareness of the existence of the judicial and legal protections against human rights violations against HIV infected and affected individuals. The effectiveness of existing policies is suboptimal and needs strengthening. One of the respondents who did not know of the existence of policies highlighted that "it is bad for us because we are people from the rural areas and thus, we are not educated and there is no one who teaches us". One of the respondents who knew of the existence of government policies pointed out the fact that because of her being in a support group, she has been taught by some of the care givers and now she knows of the policies. Another respondent noted that "yes there are policies, but it is just that we are not aware or familiar with them. Again, as much as they are there, they are just on paper; not in practice or in action".

Reporting cases of human rights violations

Various reasons were cited by respondents for not reporting their cases to the relevant authorities. The first reason relates to lack of knowledge of existing government policies and their effectiveness. Many respondents noted that they did not know that the violation could be reported. Those respondents who did report cases of human rights violations generally used the Community Health Care Workers who later referred their cases to social workers. This group of health care personnel is in constant interaction with communities and handles a lot of health related issues. One respondent explained: "I reported the case to the community health care workers and they are trying to help me but it is difficult since I do not have money to get transport to go to the district office". This shows the existence of referral systems from the community to the relevant authorities in the district, although other challenges exist like inadequate financial resources for the victim to follow up their case and receive the necessary legal support. Generally, most of the violations that were violent in nature were reported to the police although some respondents noted that the police did not know how to handle such cases. One respondent explained that “the problem was that I did not know where the place to report was because the police do not know anything about HIV even if they open a case”. One of the respondents noted that the reported case led to the “perpetrator being caught and imprisoned”.

Chapter 04 – Conclusion and Recommendations

Human rights violations are happening every day to individuals in households and communities. *Human Rights Count!* is a way of documenting such gross maltreatment of people affected and infected with HIV. The poor, illiterate, uneducated and unemployed — mostly women — bear the brunt of human rights violations which have been exacerbated by their HIV status. Families and communities which are supposed to offer care and support as well as mitigate the negative circumstances facing PLHIV very often seem to be the perpetrators of human rights violations, as has been shown by the results of this study. On the other hand, while advocacy is being done to ensure equity and equality in the provision of health services, people living with HIV still experience rights violations when they access health services. The supporting structures such as the police services do respond to the plight of PLHIV regarding human rights violations, but this needs to be optimised. More work has to be done at all levels to ensure that the rights of PLHIV are safeguarded.

Recommendations for NAPWA

Support groups are central to the provision of care and support, since communities are a place full of gross human rights violations. One respondent acknowledged the role of support groups, saying that “I am happy because I got advice and support from one of the support group members to cope with the situation”. Support groups tend to be very effective and thus NAPWA needs to extend their support into all communities to service their membership.

There is a need for continued advocacy to eliminate stigma and discrimination at all levels, starting at the family level, and this means that NAPWA together with other civil society organizations should work closely together to build a strong case and challenge existing societal attitudes and prevailing cultural norms. This work should include training their membership and communities on human rights issues to minimise cases of human rights violations.

The documentation of human rights violations should form the core of what NAPWA does, and not treat this study as a one-off research project. This work should be carried forward and become an ongoing program extended to all the areas of the Province. The documentation of such human rights violations will assist NAPWA in giving policy advice to government using an evidence-based approach.

Recommendations for civil society

The advocacy role of civil society needs to be strengthened to ensure that government and other policy makers receive evidence-based advice on human rights. This will enable them to conduct legal and policy reviews that are inclusive of PLHIV views and experiences, and to ensure a reduction in human rights violations.

An integrated community awareness program should be developed at the national level to address issues of stigma and discrimination. An integrated approach will minimise issues of duplication and comprehensively address HIV-related stigma and discrimination. It can bring communities together, create a platform for dialogue, give voice to community concerns, and find ways to deal with any issues and violations identified. Communities need to be educated on the existence of legal services that they can access if faced with stigma and discrimination.

Standards for effective support group models should be developed, offering guidance to effectively support victims of HIV-related rights violations. Evidence points to the existence of a lot of support groups but their effectiveness is compromised by the lack of standardised guidelines. The conveners of these support groups should be adequately and comprehensively trained in human and legal rights for PLHIV.

Recommendations for government

We acknowledge the existence of legislation to promote human and legal rights, and that the National HIV/AIDS and STI Strategic Plan 2007–2011 states that this should be prioritized. However, the government needs to ensure the translation of these policies into practice and also to provide an inclusive platform for policy development that ensures input from PLHIV. The government should ensure the implementation of the Greater Involvement of People living with AIDS (GIPA) principle in all HIV-related strategies. This can be achieved if government and civil society come together and develop a comprehensive operational strategy to deal with human and legal rights.

A clear human rights framework has to be developed and human rights should be mainstreamed into all HIV programmes. A justice and legal system conducive to respect for human rights needs to be established, be accessible and have a good turnaround time for dealing with cases reported to relevant authorities, especially those cases involving human rights violations against PLHIV.

The victim empowerment programme needs to be extended to reach those whose rights have been violated because of their HIV status. Furthermore, capacity building and monitoring of policy implementation should be prioritised, coupled with the extension of legal services to rural communities to ensure accessibility for those who need these services the most. There should be adequate resource allocation for the implementation of advocacy programmes to de-stigmatise HIV, raise awareness, and engage in community dialogues.

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