

CHAPTER 1: INTRODUCTION

1.1 INTRODUCING THE IDEA

1.1.1 The motivation for this study

Very often researchers will be confronted by a problem in their own lives or become aware of the problems facing people in their community. Much research is aimed at solving immediate problems in the world (Higson-Smith, 2000: 9).

On December 14 and 15, 2004, the *Associated Press* (AP) created an international media domino effect by reporting irresponsibly on the antiretroviral (ARV) drug nevirapine. (Refer to appendices A and B).

Nevirapine, administered both as a single dose (sdNVP) and as a combination drug, is highly effective in preventing the vertical or perinatal mother to child transmission (PMTCT) of the AIDS-causing virus, HIV. The AP reports charged that severe side-effects of sdNVP had been swept under the carpet by the American National Institutes of Health (NIH) during the HIVNET 012 clinical trial in Uganda between 1997 and 1999. A day later, on December 16, the AP further ran an alarmist story on the 2003 death of an American woman who suffered fatal liver failure probably due to nevirapine *continued therapy* (not sdNVP) in the US. (Refer to appendix C).

It later transpired that the AP Ugandan trial allegations were false and that the misunderstandings were sparked by administrative hiccups: there never was any indication of sdNVP side effects and to date continued medical surveillance shows that sdNVP does not result in toxicity. The damage, however, had already been done with patients eschewing nevirapine treatment and a general consensus that:

Doctors using [nevirapine] to good effect throughout Africa rightly fear the NIH fumbles could spur pressure to stop using the drug before alternatives are available....That could spell disaster for a multitude of African children ... and deprive a struggling continent of an undeniable blessing (*Minneapolis Star Tribune*, 2004).

The main motivation for this study, therefore, stems from an awareness that nevirapine misinformation is being channelled through the media to South African communities, with the result that confusion and question marks are raised over a drug which should, instead, be viewed as a lifesaver for a country grappling with a huge AIDS epidemic:

Unfortunately this issue [nevirapine] has become entangled with politics and this is also evident on the ground. There is a lot of anger among ordinary people who feel they have been used and abused by major pharmaceutical companies (Kariem, 2005).

Comments such as this by Dr Saadiq Kariem, the ANC National Health Secretary, indicate that the South African media has been lax in fulfilling the need for clear and appropriate reporting on nevirapine.

Kariem's observation further illustrates the central theme of this research: that media content is a cause for consequences in society.

1.2 INTRODUCING THE RESEARCH PROBLEM

1.2.1 The aim of the study

The empirical observation outlined above dictates that the primary aim of this study is to assess the South African print media's recent reportage on the antiretroviral drug nevirapine, both as a monotherapy and part of a combined treatment regimen in the prevention of PMTCT of HIV-1, and to ascertain how the public experiences the media's

approach. The purpose of this research is to explore the media audience's experience, be it negative or positive, of the current reporting trends in communicating a socially important aspect of complex science to the public.

1.2.2 Identifying and articulating the research problem

The focal point of this study, therefore, is the content and audience experience of nevirapine reportage in selected South African newspapers. The research objectives of such a study are to ascertain whether or not the South African print media currently covers nevirapine sufficiently well to inform and empower the public adequately.

In order to prevent the research area from becoming too wide and therefore “unresearchable”, the problem statement is translated into a more compact research question:

What is the Western Cape public's experience of nevirapine reporting in three selected local newspapers?



1.2.3 An indication of how the research question evolved from preliminary reading

A preliminary literature study revealed that no South African research has to date focused on the media's treatment of nevirapine, the drug which plays a key role in preventing the second greatest cause for the spread of AIDS, the mother to child transmission (MTCT) of HIV. My research, therefore, draws on the approaches and results supplied by an initial reading of studies into the science reporting of HIV/AIDS issues in general.

Elizabeth Galloway's research has shown that there is a distinct lack of in-depth science reporting on HIV/AIDS issues in South African newspapers (Galloway, 2001). Professor Gideon de Wet backs this up: “little information about the clinical aspects of the disease is available [in the print media]” (De Wet, 2003: 110).

Further research on the causes of superficial reporting on AIDS suggests that limited resource contact between scientists and the media plays a part (Gething, 2001) as well as the mainly political content of reports on HIV/AIDS issues (De Wet, 2003).

These research findings encouraged the researcher to pursue the existing body of knowledge in an attempt to ascertain the prevalence of these findings today with a specific focus on nevirapine.

The preliminary review suggested a combined approach of content analysis, in-depth interviewing and a community-based survey to evaluate both the writing and the reception of nevirapine reporting.

An unanswered question: the niche for this study

The reader's perception of news plays a role in forming personal opinion and it is here that the preliminary study provided this research with a niche within an already existing body of knowledge. Although South African research, Gething (2001), Galloway (2001) and De Wet (2003), studies the content of AIDS reporting and the reasons why science writing on HIV/AIDS is unsatisfactory, their research does not include the consequences (the public's experience) of AIDS reporting.

This research, in its focus on the public's perception of nevirapine reporting, will encompass the issue of gender balance in the media. My involvement with Gender Links (an NGO which focuses on gender representation in the media) in the Southern African Gender and Media Audience Research in 2004, has equipped me with a better understanding of female presence in the media. This awareness is of great importance to my proposed research which focuses on an issue which impacts directly on women's decisions as mothers. I will in part, therefore, draw on the methods and results of this study to validate aspects of my own research.

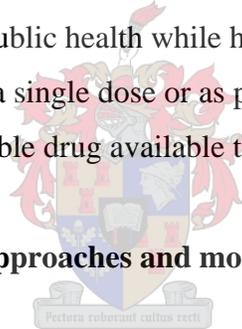
1.3 INTRODUCING THE STUDY RESEARCH DESIGN

1.3.1 The overarching paradigm of this research

The dominant perspective expressed in this study is that the media has an informative function upon which the public relies to guide them in their decision-making. The way in which the press reports on nevirapine determines either a positive or negative audience experience of issues pertaining to the drug.

Functions of the press are dealt with in the next chapter: it is therefore sufficient to mention at this point that the South African AIDS context demands a socially responsible role from journalists when reporting on the epidemic. Clinically correct and accessible information on nevirapine, via the media, will empower the public in making their own decisions regarding issues of life or death. Science reporters must be advocates for the public, writing in the interests of public health while holding on to the thought that nevirapine, administered either as a single dose or as part of a combination regimen, is a cheap, highly effective and accessible drug available to women to curb the AIDS swell.

1.3.2 Methodology overview: approaches and modes of observation



The research is empirical using the grounded theory approach which allows deductions to be made from observations (De Wet, 2004). One begins with an area of study and allows images, views and ideas (themes) to emerge from the material (De Wet, 2004).

The research methods employed in this study are used to study media content as a cause for effect on the audience. As stated, the purpose of this research is to answer the question “What is the Western Cape public’s experience of nevirapine reporting in three selected local newspapers?”

It is difficult to study effects without intelligent reference to content as audiences are always defined at least in part by media content (as cause), therefore we cannot study audiences without studying content (McQuail, 2000: 305 and 306). The primary method

of data collection is thus a content analysis: a structured study of newspaper reports chosen over a recent time frame.

Once the content analysis is complete, in-depth interviews with editors and journalists from the three selected newspapers will be carried out to address the meta issues (the reasons for the status of nevirapine reportage) surrounding the text content:

As categories and patterns emerge [from a grounded theory approach] the researcher should examine the explanations and begin to look for new or different possibilities.... This requires the researcher to understand the meta issues that provide the research context (De Wet, 2004: 104).

This interviewing process enhances the research by providing depth and validity to the author's own interpretation of the chosen texts and can be described as a "thick"¹ description.

On completion of the content analysis and interviews, the next step is to do an exploratory audience reception analysis through a focus group study with HIV affected members of the public and interviews with AIDS specialists, as "the future of content analysis, one way or another, has to lie in relating 'content' as sent to the wider structure of meanings in society" (McQuail, 2000: 329).

The research will be both quantitative and qualitative in nature as it will provide:

- descriptive statistics, through quantitative content analysis
- themes, through qualitative content analysis and in-depth interviews
- a "thick" qualitative interpretation of the meta issues in the content analysis through in-depth interviews with journalists and editors

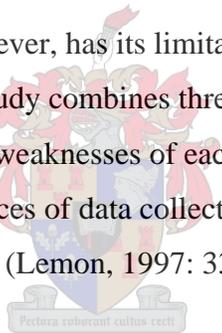
¹ "A thick description does more than record what a person is doing. It goes beyond mere fact and surface appearances. It presents detail, context, emotion and the webs of social relationships that join persons to one another" (Denzin in Mouton 2001: 188).

- a qualitative exploration of the public’s media experience of nevirapine through interviews with AIDS specialists and a focus group study of HIV positive mothers

1.3.3 Research reliability

This study is a process of exploration to discover how and why the public experiences the print media’s management of a particular issue. As with all research, the ultimate purpose of the study is to contribute to solving a problem within society. The correct identification and explanation of the research problem is therefore of great importance, in other words the research and its conclusions must be reliable.

Each method of data collection, however, has its limitations which can impact on the reliability of research results. This study combines three methods of data collection in an effort to compensate for the relative weaknesses of each method. This system of triangulation “includes multiple sources of data collection in a single research project to increase the reliability of the results” (Lemon, 1997: 33).



1.4 OVERVIEW OF THE REMAINDER OF THE THESIS

The motivation, aim, South African context and methodology for this study have hitherto been identified.

The following chapter consists of a detailed literature review of the issues pertinent to this research. This review further contextualises the research problem and provides a theoretical framework which guides the empirical structure of the study.

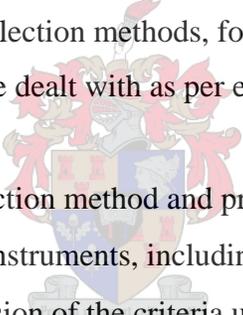
The importance of a scientifically correct and gender-sensitive approach to nevirapine reporting is emphasised by an overview of the graveness of the AIDS epidemic in South

Africa, the clinical and historical complexity of the drug nevirapine itself and the female and cultural issues which play a significant role in the spread of HIV.

The definition of basic media theories, identification of reality-distorting media policies and suggested guidelines for science and AIDS reporting provide the researcher with a reliable gauge against which to evaluate the status and quality of nevirapine reportage in South African newspapers.

Chapter 3 documents the research design and methodology in detail. Key expectations and variables are identified as well as an indication of how these expectations were arrived at from the preceding literature review or borrowed from previous research.

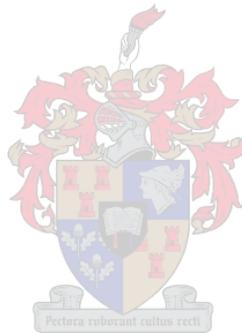
Key research questions which guide the categorising of units for analysis are laid out. This study comprises three data collection methods, for which reason the following points in the research design will be dealt with as per each method:

- 
- full details of the data collection method and process
 - a discussion of measuring instruments, including their reliability
 - sample profile and a discussion of the criteria used in the choice of samples
 - data capturing and data editing
 - data analysis
 - a discussion of the quality of the data collected

Chapters 4, 5 and 6 document the research findings in the form of graphs, tables and notes. These results are then discussed in relation to the previously stated expectations. An interpretation of both the positive and negative findings is offered.

Chapter 7 draws together the results from the previous chapters. The main research findings are highlighted and conclusions drawn. These results and conclusions are then related to the theory and literature in the study domain by connecting the findings to aspects of the literature reviewed in Chapter 2.

An honest discussion of anomalies and unexpected results marks the completion of the research. Thereafter the discussion moves beyond the hypothesis and the implications of the findings are examined à propos media policy implications and suggestions regarding future research.



CHAPTER 2: LITERATURE REVIEW

2.1 SETTING THE THEORETICAL FRAMEWORK

2.1.1 Indicating the literature covered

Certain fields of literature were demarcated as a corner-stone of this study to provide a research context and theoretical framework.

This study is based on the expectation that South African print journalists mismanage reporting on the antiretroviral drug nevirapine and that the public experiences said reporting in a negative manner. In an attempt to ascertain whether or not this is true, certain theoretical frameworks need to be set in place against which to measure/evaluate the newspaper coverage of nevirapine.

A broad definition, therefore, of the media is necessary. The overarching paradigm of this research is functionalist and so I will refer to McQuail's functionalism media-society theory. I chose this theory because "[it] posits that the more an audience is reliant on the mass media for information *and* the more a society is in a state of crisis or instability, then the more power the media are likely to have (or be credited with)" (McQuail, 2000: 79).

This theory provides a useful framework of reference for my purposes which is to establish whether or not the media gives correct attention to the urgent social needs of South Africans (who are in the grips of an AIDS crisis and who, through a lack of satisfactory science education at school, need the media to feed them accurate scientific information) when reporting on nevirapine. According to McQuail's theory "media function can refer both to more or less objective tasks of the media (such as news or editorialising) and to purposes or utilities as perceived by a media user (such as being informed or entertained)" (McQuail, 2000: 79).

Media processes through which news is channeled to the public also form part of this theoretical framework. Gatekeeping, agenda-setting and news values, as later discussed,

aid in this analysis of the presentation of nevirapine to the public. Tied to this is the possible distortion of reality by the media in its “creation” of news and the question of whether the media can be trusted as a true messenger of reality or not.

The revision of functionalist media theories and news processes and their possible effects on the media audience dealt with later in this chapter relies on the expertise of recognised media theorists.

Further to this it is necessary, for the purposes of this study, to have a framework by which to judge good science and HIV/AIDS reporting. It has been said that science journalism is the most difficult form of journalism (Mitchell, 2005). This is because science writers often have to explain difficult and complex issues to the layperson. It is, however, vital for journalists to report clearly and accurately on science because readers who have accurate information are able to make responsible decisions about vital issues such as health and well being.

This study evaluates the quality of South African science reporting, with a focus on reporting on HIV/AIDS, based on the guidelines provided for journalists by international research organisations and authors specialised in science writing for the public. These sources were chosen because of their emphasis on accuracy and ethics.

It is impossible to consider a content analysis of nevirapine (a drug available to pregnant HIV positive mothers who want to protect their unborn children from the HIV virus) without ascertaining to what degree women’s opinions are voiced through the media.

Recent South African research provides perspective on the perception and portrayal of women in the media. Linked to this is a review of how the South African patriarchal society views women. This cultural take provides a useful framework against which to measure whether or not this patriarchal view is perpetuated within the context of the media’s reportage of nevirapine.

The importance of the role of media representation of nevirapine within the South African cultural context becomes evident on the consideration of the enormity of the AIDS epidemic in this country and the role the drug can play in preventing one of the major causes of the spread of AIDS – the transmission of the HIV virus from mother to child during pregnancy or birth.

It is therefore appropriate that the following literature review is introduced by an overview of South African AIDS statistics and the therapeutic role nevirapine can play in the vertical transmission of the HIV-1 virus.

2.2 CONTEXTUALISING NEVIRAPINE WITHIN THE AIDS EPIDEMIC IN SOUTH AFRICA

2.2.1 AIDS statistics in South Africa

...the HIV/AIDS epidemic in South Africa is raising the mortality levels of prime-aged adults (Pali Lehohla, February 2005).

The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organisation (WHO), in their 2004 report on the global AIDS epidemic, state that approximately 38 million adults and children worldwide are infected with the AIDS-causing HIV virus. The report estimates that 25 million of these people live in sub-Saharan Africa where, in 2003, an estimated three million people became newly infected and 2.2 million died (75 percent of the three million AIDS deaths globally that year). South Africa has the highest number of HIV positive people in the world with 5.3 million infected. (UNAIDS/WHO Working Group, 2004). The figures for South Africa have been recently borne out by the South African mortality report.

In February 2005 Statistics SA released the report: Mortality and Causes of Death in South Africa from 1997 to 2003. The results of the report are based on the analysis of a substantial sample of death certificates. The data, in the words of Statistician General, Pali Lehohla, gives “indirect evidence that the HIV/AIDS epidemic in South Africa is

raising the mortality levels of prime-aged adults” (Lehohla quoted in *Medical News Today*: 2005).

According to the report, the annual number of registered deaths rose by 57 percent between 1997 and 2002. A 116 percent rise in deaths between the ages of 25 and 49 indicates that this age group accounted for 34 percent of deaths in 2003 as opposed to 23 percent in 1997 (Noble, Berry and Fredriksson, 2005).

An analysis of the report results by the Medical Research Council (MRC) shows that rates (deaths per thousand) had increased according to a “distinctive age-specific pattern”. The greatest increases were in the age groups 0-4 and 25-49 years, while death rates among teenagers and older people remained stable. In short, according to the MRC results, “HIV caused the deaths of 53,185 men aged 15-59 years, 59,445 women aged 15-59 years, and 40,727 children under 5 years old in the year 2000-2001” (Noble *et al*, 2005), which means that 74 percent of deaths for children under five during this period were AIDS-related (Medical News Today: 2005).

The MRC estimates are reinforced by the Actuarial Society of South Africa (ASSA) which, by means of a computer simulated model called ASSA2000, states that HIV caused 165,859 AIDS-related deaths in 2000. These deaths constitute 30 percent of their estimated total of 556,585 deaths (Noble *et al*, 2005).

The ASSA2002 model calculates that 311,000 people died of AIDS-related illnesses in 2004 - comprising 44 percent of all deaths. Among adults aged 15-49 years, it estimates that 70 percent of all deaths were due to AIDS (Noble *et al*, 2005).

The highest numbers of all come from UNAIDS/WHO. They estimate that AIDS claimed 370,000 lives in 2003 - more than 1,000 every day (Noble *et al*, 2005).

Results from these various reports clearly indicate that:

- the AIDS epidemic is still on the increase in South Africa
- more women than men are infected and dying from the disease

- young teenage girls (possibly as young as 14 or younger) become infected with HIV
- infant death through MTCT is steadily rising

2.2.2 Women, culture and HIV/AIDS

More than any other health crisis, AIDS has exposed the social and economic inequities that surround us and reside within us. To make prevention work, especially for women and girls, we must promote and protect their human rights. We must work within cultures to challenge the social norms that contribute to the lower status of women and girls and that condone violence against them (Thoraya Ahmed Obaid, Executive Director, UNFPA, 2004).

The majority of women and young teenage girls in South Africa are at the mercy of a patriarchal society where inequalities in the boardroom and the bedroom abound. Within the context of HIV/AIDS this gender inequality threatens the lives of far more women than men:

Culturally – entrenched gender roles and norms about sexuality help to fuel the spread of HIV/AIDS, and women and girls are particularly vulnerable to infection because of the cultural practices and norms which continue to keep women in a position of inequality (Nkutha and Mtintso, 2004: 73).

Figures cited in the UNAIDS/WHO 2004 report on the AIDS pandemic are sombre proof of this cultural affliction:

African women are at greater risk, becoming infected at an earlier age than men. Today there are on average 13 infected women for every 10 infected men in sub-Saharan Africa – up from 12 for 10 in 2002. The difference is even more pronounced among 15 to 24 year olds. A review compared the ratio of young women living with HIV to young men living with HIV; this

ranges from 20 women for every 10 men in South Africa (UNAIDS: 2004).

There are several ways in which gender inequality, imposed by culture, hinders women's fight against AIDS:

1. A key concept in curbing the spread of AIDS is the practice of safe sex, but:

Because of the unequal power relations between men and women, women are not able to negotiate safer sex especially where the only known method for reducing the spread of the disease (short of abstinence) is the condom – a device almost exclusively controlled by men (Lowe Morna, 2004: 18).

2. “Gender inequality and poverty go hand in hand, and the two feed HIV/AIDS” (Seidman, 2004: 83). Conventional African wisdom dictates that young women should marry men considerably older than themselves to protect them financially. Inevitably, however, these young women all too often become infected with HIV by unfaithful husbands (Oriang, 2004: 6). In addition to this “Women living in poverty may adopt behaviour that exposes them to HIV infection, including the exchange of sex for food, shelter or money” (Seidman, 2004: 83).

3. The common traditional practice of a man having sex with a virgin to cure himself of AIDS, fuels the power imbalance between men and women and inflicts a death sentence on the latter (Lowe Morna, 2004: 18).

4. Cultural beliefs pressurise women and girls to remain ignorant about sexual matters, an ignorance which prohibits self-protection against HIV infection. These beliefs state:

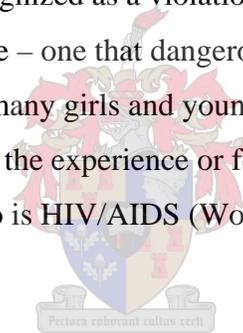
- mothers cannot talk about sex to their daughters: it is the duty of the aunt
- when a girl falls pregnant, she should not let her parents know
- anything related to sex and reproductive organs is taboo, so child abuse cannot be reported to the authorities

- culture does not allow children to be too close to their parents; parents wield too much power for the children to be able to open up
- women should learn in silence
- women should not question men on anything

(Nkutha & Mtintso, 2004: 73).

A woman's cultural vulnerability to HIV infection is compounded by an inescapable biological vulnerability when forced sex results in tearing of the vaginal wall, allowing HIV infected sperm direct access to the woman's bloodstream:

Women are physically more susceptible to HIV infection than men, and gender-based violence makes them even more vulnerable. Violence against women is well recognized as a violation of human rights and also now as a public health issue – one that dangerously intersects with the HIV/AIDS epidemic. For many girls and young women, their first sexual encounter is often coerced; the experience or fear of violence is a daily reality, and increasingly, so is HIV/AIDS (World Health Organisation, 2004).



The nexus between gender inequality and babies contracting HIV from their infected mothers during pregnancy or birth is a logical conclusion. A woman who cannot negotiate safe sex is open to both HIV infection and pregnancy. Research has shown that, without medical intervention, there is the possibility of as much as a 45 percent transmission rate of HIV from mother to child (Birth.com.au, 2004).

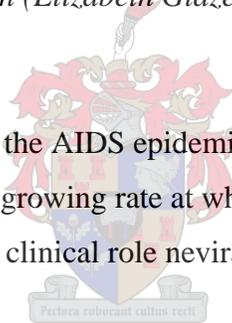
It is the responsibility of media communicators to play a role in preventing the spread of AIDS by accurate and sensitive reporting on the educational, social/cultural, clinical and treatment aspects of the disease: they will do this far more effectively if they have an in-depth understanding (and a subsequent heightened sense of compassion and social responsibility) of how African cultures fuel gender inequality and so disempower women in the fight against HIV infection.

Good HIV/AIDS reporting, which does not shy away from the dissemination of those cultural issues which feed the AIDS epidemic, will enlighten both women and men and better equip them to play a responsible role in the fight against AIDS. In conclusion, “The media can play a constructive role by providing a forum for debate and analysis of the cultural practices in a society” (Nkutha & Mtintso, 2004: 76).

2.2.3 Nevirapine monotherapy and combined therapy as an effective treatment in curbing the AIDS epidemic in resource poor settings

UNAIDS estimates that 1,900 children worldwide are infected with HIV each day, the vast majority through mother-to-child transmission....At this point in time, based on all the existing scientific evidence, nevirapine should continue to be one of several interventions available to prevent mother-to-child transmission (Elizabeth Glazer Pediatric AIDS Foundation, 2004).

Having established the enormity of the AIDS epidemic in South Africa, the increase in infant AIDS-related deaths and the growing rate at which women are contracting the HIV virus, it is now time to consider the clinical role nevirapine can play in controlling the disease.



The prevention of PMTCT of HIV is a key factor in preventing the spread of AIDS. PMTCT of the HIV virus is the second leading mode of transmission (Campbell, 2003:2). It is estimated that babies in developing countries (such as South East Asia, Africa and South America) have a 30 to 45 percent chance of becoming infected with HIV by their mothers during pregnancy or birth. This vertical transmission of the virus is far lower in developed countries with a 15 to 30 percent risk due to better access to drugs which prevent MTCT (Birth.com.au, 2004).

There are various antiretroviral medications (ARVs) or ARV combination therapies which significantly reduce PMTCT. The use of these drugs depends on whether treatment is given during pregnancy, during labour or to mother and child after birth. More expensive combined therapies, which require advanced health infrastructures for the

monitored administration of lengthier regimens, are used extensively in the developed world. Developing nations, such as those in Africa, rely largely on cheaper, simpler regimens which are well-suited to resource-poor settings (RPS) with an inadequate health infrastructure (Aidsmap, 2004: 1).

ARVs, in simple terms, reduce (but never eliminate) the amount of HIV in the blood stream (viral load). The drugs achieve this by preventing the HIV enzyme 'reverse transcriptase' from functioning. It is this enzyme the virus relies on "to incorporate its own genetic material into host [CD4] cells, which then allows it to reproduce freely" (Saloojee, 2002:1). The drug action decreases the viral load, allowing the CD4 (the T – helper cells) to increase, which results in an improved immune system and lowers the risk of death via the onset of an AIDS-related opportunistic infection. A woman who has a reduced viral load is less likely to transmit HIV to her baby during pregnancy and birth (Birth.com.au, 2004).

The preferred treatment for PMTCT is triple combination antiretroviral therapy (ART) but this not a viable option in RPS or countries where limited finances prevent public health systems from providing ART to all the pregnant women who need it (Aidsmap, 2004: 1). Alternative short treatment courses are, instead, a realistic option for PMTCT in RPS such as sub-Saharan Africa.

The WHO 3 by 5 Initiative (treat three million people living with HIV/AIDS by 2005) convened an expert consultation in Geneva in February 2004 to decide on appropriate ARV use for PMTCT in RPS. The WHO's most up-to-date key recommendations include:

- Women who do not need treatment, or do not have access to treatment, should be offered ARV prophylaxis to prevent MTCT using one of a number of ARV drug regimens known to be safe and effective
- The most efficacious regimen among those recommended for prevention of MTCT for women with HIV who do not need ARV treatment is zidovudine

- (ZDV) from 28 weeks with single dose nevirapine (nevirapine) at onset of labour for the mother and single dose nevirapine plus one week ZDV for the infant
- Alternative but less efficacious regimens include one based on ZDV alone (from 28 weeks of pregnancy and through labour for the mother and for one week for the infant), one using the combination of ZDV plus lamivudine (3TC) (from 36 weeks of pregnancy, through labour and one week postpartum for the mother, and for one week for the infant), and a regimen comprising a single dose of nevirapine to the mother and to the infant (which does not need to be initiated until labour)
 - The selection of the ARV drug regimen should be made at national level, based on issues of efficacy, safety, drug resistance, feasibility, and acceptability (WHO, 2005).

For the purposes of this study detail will be provided on the use of nevirapine as recommended above as both a single dose and in combination with ZDV.

Nevirapine is manufactured by Boehringer Ingelheim (BI) and goes by the trade name Viramune. The South African government currently receives nevirapine from BI at no charge. The drug belongs to a class of drugs known as non-nucleoside reverse transcriptase inhibitors (NNRTI). Nevirapine prevents the HIV-1 enzyme, 'reverse transcriptase', from encoding its own genetic information onto the CD4 host cell [and thus enabling the virus to make further copies of itself] (Saloojee, 2002: 1). Nevirapine has been particularly successful in the prevention of PMTCT because it "readily crosses the placenta and achieves neonatal blood concentrations comparable to those in the mother" (Aidsmap: 2004: 2).

The 1999 Ugandan-based HIVNET 012 study showed that the administration of a single dose of nevirapine to the mother during labour and a single dose to the infant within 72 hours of birth reduces the risk of vertical transmission by up to 47 percent (Aidsmap, 2004: 5). This simple and inexpensive regimen has, over the past years, proved to be a highly successful means of preventing the vertical transmission of HIV in RPS where limited finances and lack of access to health centres have prevented the administration of more expensive, lengthier treatments.

Further to this, ongoing trials in South Africa show that sdNVP continues to act as an effective drug in preventing PMTCT if mothers (who are unable to formula-feed consistently) are disciplined in exclusive breastfeeding (Grobelaar, 2005)². This recent evidence supports the finding in an 18-month follow up from the HIVNET 012 trial where breastfed babies at 14 weeks and 12 months of life had HIV transmission rates of 13 and 15.7 percent respectively. These results suggest that:

...the reduction in the risk of transmission associated with nevirapine prophylaxis persists for at least the first year of life, despite the ongoing risk of breastfeeding. Nevirapine was more effective in reducing transmission than AZT in [breastfeeding] women with CD4 counts below 200 (Aidsmap, 2004:5).

The dual benefit of sdNVP in enabling HIV positive mothers to breastfeed in RPS where clean water and lack of finances often prohibit formula feeding; and in presenting an effective treatment alternative to more complicated treatments requiring drug administration either throughout pregnancy or in the last month of pregnancy, highlights the very special role this drug plays in PMTCT in RPS.

Although the benefits of sdNVP persist, however, ongoing HIV research recommends the use of “more aggressive combination drug regimens that maximally suppress viral replication” (Public Health Service Task Force, 2005).

A recent study conducted in Thailand shows that “a single dose of nevirapine to the mother, with or without a dose of nevirapine to the infant, added to oral zidovudine prophylaxis starting at 28 weeks of gestation, is highly effective in reducing mother-to-child transmission of HIV” (Lallemant, Jourdain, Le Coeur, Mary, Ngo-Giang-Huong, Koetsawang, Kanshana, McIntosh and Thaineua, 2004:228). It is on the basis of this research that the February 2004 WHO convention decided that:

² “Mixed feeding, using both breast milk and formula milk, compromises the neonate’s delicate gut, causing ruptures in the intestinal lining and thereby facilitating HIV transmission into the infant’s bloodstream” (Grobelaar: 2005).

until further evidence is available...the ZDV plus single-dose nevirapine regimen can be recommended for the prevention of MTCT because of its considerable efficacy in reducing MTCT (by 80%, from the transmission rates observed with short course ZDV alone , down to an absolute level under 2%), its simplicity and its safety profile for mother and infant (WHO, 2005).

Despite its proven clinical efficacy and the WHO's recommendation, however, ZDV plus sdNVP is not always a viable option in RPS as many women only present at clinics to give birth and not before. The reasons for this are largely twofold: an inability to access far-away healthcare regularly due to lack of transport; or simply a fear of stigma which prevents HIV positive pregnant mothers from presenting at clinics before birth.

Under these circumstances ZDV plus sdNVP “is unlikely to quickly supplant the simpler sdNVP alone regimen in many settings” (Aidsmap, 2004: 1). It is in circumstances such as these that sdNVP can play a unique role in PMTCT: “If an HIV positive woman in labour presents at a health care centre for the first time I do not hesitate to administer sdNVP” (Grobbelaar, 2005).

Toxicity and the emergence of drug-resistant HIV strains have long caused concern over the use of nevirapine. It is true that the long-term use of nevirapine alone or in combination with other drugs can result in severe life-threatening conditions such as liver failure (Saloojee, 2002: 2). The South African Intrapartum Nevirapine Trial (SAINT), however, has shown that the administration of sdNVP “when taken in a short-course for PMTCT, does not cause significant toxicity in mothers or babies” (Elizabeth Glaser Pediatric AIDS Foundation, 2004: 1). Based on this “current thinking is that the proven benefits in avoiding HIV infection outweigh possible rare side-effects of drug exposure” (Aidsmap, 2004).

Possible resistance to post-natal combination therapies incorporating NNRTI drugs (such as efavirenz) for the treatment of AIDS in women and infants who received either sdNVP during labour or after birth respectively, or sdNVP plus ZDV has raised concern about

the use of nevirapine in PMTCT. Studies have shown that “a single intrapartum dose of nevirapine for the prevention of mother-to-child transmission of the human immunodeficiency virus (HIV) leads to the selection of resistance mutations” (Jourdain, G., Ngo-Giang-Huong, N., Le Coeur, S., Bowonwatanuwong, C., Kantipong, P., Leechanachai, P., Ariyadej, S., Leenasirimakul, P., Hammer, S. and Lallemand, M., 2004: 229). New data, from the Thailand study mentioned above, “suggest that the regimen of ZDV and single-dose nevirapine regimen could dampen the mother’s response to ARV treatment initiated in the first months after delivery” (WHO, 2005).

Perspective on nevirapine resistance, however, is provided by various meta issues:

- Of primary importance is the understanding that nevirapine causes resistance in the HIV virus because *low levels* [italics own] of the drug persist in the bloodstream approximately 14-21 days after taking a single dose (Aidsmap: 2004:2). This means the stronger surviving HIV-1 viruses are able to build up resistance to the remaining low levels of nevirapine and hypothetically survive future drug applications from the NNRTI group
- The impact of the risk of resistance remains clinically unproven: “Whether there are clinically significant consequences in mothers who are subsequently treated with a nevirapine-containing regimen is unknown” (Jourdain *et al*, 2004: 229)
- Resistance does not interfere with the efficacy of the prevention of PMTCT (Saloojee, 2002:2)
- The frequency of nevirapine resistance mutations has been reported to decrease with the time after exposure to nevirapine (Jourdain *et al*, 2004: 236)
- Strategies are already available that maximize both the prevention of mother-to-child transmission of HIV and antiretroviral treatment options for mothers (Jourdain, 2004: 238)
- One such strategy is the provision of additional ARVs immediately after intrapartum nevirapine which suppress viral replication during the period in which plasma nevirapine levels remain detectable (Jourdain, 2004: 238)

- Further strategies worth mentioning, although they are not directly relevant to this study, include the use of triple therapy during pregnancy when feasible and desirable or initiating therapy with a protease-inhibitor–based regimen (Jourdain, 2004: 238)
- Researchers propose therefore that the emergence of resistant mutations is not sufficient reason to delay the implementation of this effective intervention [sdNVP] in resource-poor settings (Aidsmap, 2004: 5).

With the above facts firmly in place it is easy to echo the words of the South African branch of *Médécins Sans Frontières* AIDS relief worker, Marta Darder: “The hypothetical risk of creating resistance does not outweigh the risk of giving birth to an HIV-positive baby, in a context where so few people access treatment anyway” (Darder quoted in Plusnews, 2005).

2.2.4 The Complexity of Nevirapine: a chronological take

Scientists and non-scientists...alike have all entered into the fray arguing the merits of the drug, its benefits, toxicities and resistance patterns. It's been condemned as 'the drug from hell' by AIDS dissident David Rasnick while heralded as a 'godsend' by many health professionals. Amidst all the rhetoric, the larger scientific and lay communities have had few opportunities to decipher the real value of the drug except through public slanging matches played out in the courts, parliament and in the media (Saloojee, 2002: 1).

For the purposes of this study it is necessary to consider the complexity of nevirapine above and beyond its straightforward clinical role within the South African context. In South Africa, perhaps more than in any other country, nevirapine has been portrayed as a highly controversial and complex issue rather than simply as a scientifically-approved treatment to help prevent the spread of AIDS.

Nevirapine has been subjected to a rollercoaster ride of conflicting press reports which have included court room battles, good press, alarmist risk reporting, inaccurate

communication of facts and the setting of political agendas. This complexity hinges on the South African leadership's inability to fully confront and commit to the AIDS epidemic and so support nationally realistic HIV prevention programmes.

Government's lack of commitment to AIDS in South Africa can be seen as reflected in its inadequate amount of spending on the disease in proportion to GDP. In the Abuja Declaration in April 2001, African leaders pledged to allocate at least 15 percent of government expenditure to the improvement of the health sector to better combat HIV/AIDS (Martin, 2003: vii). Although South Africa has fulfilled the commitment made in Ajuba, this does not mean that it has responsibly embraced its own HIV/AIDS epidemic.

A recent HSRC study probed the quantities of government funds made available for HIV/AIDS in six southern African countries: Botswana, Lesotho, Mozambique, South Africa, Swaziland and Zimbabwe. According to the study "South Africa spends 3 percent of GDP and just over 15 percent of government expenditure on health care" (Martin, 2003: 27). Of this three percent 0.03 percent is spent on HIV/AIDS: a low percentage considering South Africa accounts for 90 percent of the total GDP for the above countries (HSRC, 2003: 45) and has the highest number of people living with HIV/AIDS in the world. The study revealed that Botswana's expenditure on the disease is the highest of the six countries when measured as a percentage of GDP (0.9 percent), then Mozambique (0.4 percent), Swaziland (0.1 percent), Lesotho (0.07 percent and lastly South Africa (0.03 percent). Figures in this category were not available for Zimbabwe (Martin, 2003: 45).

A brief chronological overview of nevirapine's history within the ARV context and Mbeki's AIDS dissidence will illustrate how a lack of appropriate leadership in the midst of a national health crisis has opened the stage to many players who pontificate on the drug for political gain. These players, amongst them AIDS dissidents, are intent on setting their own agendas and operate from a poor scientific knowledge base, creating confusion amongst the community - a community dependent on simply-relayed scientific fact on which to base decisions for the good of their unborn children.

June 21, 1996: The United States Food and Drug Administration (FDA) approved nevirapine for the use in combination with other ARVs for the treatment of HIV-1 infection (Aidsinfo, 2005: 1).

1997: The clinical trial called HIVNET 012 is started in Uganda to address the developing world's urgent need for the effective, cheap and safe regimens for the PMTCT of HIV. The study was funded by the National Institutes of Health's (NIH) National Institute of Allergy and Infectious Diseases (NIAID) and focused on sdNVP as a potentially effective treatment for PMTCT. (NIH, NIAID, 2004: 3).

1998: Nevirapine was first registered in South Africa for the treatment of HIV-1 infection by the Medicines Control Council (MCC).

September 1999: *The Lancet* published the results from the HIVNET 012 study which show that sdNVP reduces the risk of MTCT of HIV-1 by up to 50 percent (NIH, NIAID, 2004: 3).

January 2000: The start of President Thabo Mbeki's AIDS dissidence. There are allegations that Mbeki was in contact with David Rasnick, chemist and prominent AIDS dissident who has long argued that AIDS is not infectious. Rasnick claims that Mbeki personally telephoned him telling Rasnick that he was planning "a public airing" of issues such as whether AIDS is sexually transmitted and whether HIV causes AIDS (Schoofs, 2000).

March 2000: The peak of Mbeki's AIDS dissidence as he questions whether or not HIV causes AIDS. As a result already tense relations between the South African government and frontline AIDS doctors, scientists, and activists, who accuse the government of shirking its duty to combat the raging epidemic, are exacerbated. Most importantly:

it raises profound questions about Mbeki's leadership on the most pressing health issue facing southern Africa (Schoofs, 2000).

There are concerns that Mbeki's call for a review of AZT (the drug used for PMTCT of HIV before sdNVP was registered for such use) was based in part on dissident writings (Schoofs: 2000). "[Dissident Anthony] Brink's work on the drug AZT was widely read by South African leadership, and prompted President Thabo Mbeki's early criticism of the drugs being used in AIDS care" (Scheff: 2004). If so, "it would mark the only time that their opinions have influenced a government decision to withhold life-saving medication" (Schoofs, 2000).

April 2000: Following the death of five South African women in the local FTC 302 trial, the first concerns over the potential negative side-effects of nevirapine are raised by the South African Minister of Health, Manto Tshabalala-Msimang. Policy decisions regarding the use of the drug in South Africa are halted and the minister states that, due to cost, few South Africans would ever derive any benefits from the drug (Health Systems Trust, 2000).

July 2000: Results from the South African Intrapartum Nevirapine Trial (SAINT) further confirm the efficacy of sdNVP in for the treatment of PMTCT of HIV (Moodley, 2000).

August 2000: Following the 13th International AIDS Conference in Durban and a follow-up meeting attended by the Minister and the MCC, the Minister of Health announced that nevirapine would still not be made generally available. Instead each province was going to select two sites for further research and the use of the drug would be confined to such sites (*Sunday Times*, 2002)

January 2001: sdNVP approved by the WHO for the effective PMTCT of HIV (WHO, 2001)

November 2000 and April 2001: the MCC worded the nevirapine package insert to the effect that the drug can be used as a single dose for the prevention of MTCT of HIV. The insert was formally approved by the Council in April 2001 (*Sunday Times*, 2002).

August 2001: The Treatment Action Campaign (TAC) steps up its pressure on government (to make nevirapine *widely* available to all pregnant mothers who need it) in an application in the High Court in Pretoria on 21 August 2001 (*Sunday Times*, 2002).

14 December 2001: The High Court orders the government to make nevirapine available to all mothers who give birth in the public health sector, and to their babies, in public health facilities where counselling is available (*Sunday Times*, 2002).

March 2002: First concerns over HIVNET 012 study are raised by the MCC. The NIH in the US launched an investigation into the conduct of this trial. “The investigation reviewed whether the patient data supported the results used by the MCC to approve the inclusion of nevirapine as a single agent for this indication” (MCC, 2003).

May – July 2002: TAC takes the government to court in its demands to the government to supply nevirapine to HIV positive pregnant mothers

5 July 2002: The Constitutional Court rules that government must provide nevirapine to all HIV-positive pregnant mothers (Baleta, 2002).

August 2002: The MCC said last week that it has decided to review the registration of nevirapine because it had concerns about the drug's efficacy and toxicity (Baleta, 2002).

2002: The emergence of AIDS dissident Anthony Brink's online publication: *The Trouble With Nevirapine* in which Brink, a South African lawyer, scrutinizes nevirapine studies and approval processes. This publication emotionally, incorrectly and inappropriately attacks the drug and any clinical trials pertaining to the drug. The following is an excerpt of Brink's criticism of the FTC 302 clinical trial using coviracil in combination with nevirapine and two other drugs, lamivudine and stavudine:

Eager to cut a slice of the AIDS-drugs action, it [Triangle Pharmaceuticals, an American pharmaceutical corporation] needed some guinea pigs on which to try out its experimental drug Coviracil (Emtricitabine, *alias* FTC), ahead of a licence application to the FDA.

Penurious South African blacks being ideal. Being unimportant and dispensable. Not such a fuss if they get hurt or killed (Brink, 2005: 30). (See appendix D for further excerpts).

March 2003: MCC withdraws its approval of nevirapine as a single agent in reducing the risk of HIV transmission from mother to child. This follows concerns raised about the HIVNET 012 study in March 2002, since which time findings indicate that the study, as a primary source of information for approval of this indication, no longer meets regulatory requirements (MCC, 2003).

April 2003: The year-long investigation by the NIH into sdNVP for the treatment of PMTCT of HIV finds that the drug is safe and effective (Altenroxel, 2003).

July 2004: The MCC announces its decision to stop recommending sdNVP to reduce MTCT of HIV because its use significantly increases the chance of drug resistance. The MCC now recommends administering nevirapine in combination with zidovudine (Kaiser, 2004).

July 2004: AIDS experts at the XV International AIDS Conference in Bangkok say the MCC's decision shows a "reluctance to confront the AIDS epidemic head-on". Joep Lange, International Aids Society president and co-chair of the AIDS conference, said that the MCC's decision sends a "totally wrong message....We know that in many settings the single dose of nevirapine ... is better than nothing" (Kaiser, 2004).

12 and 14 December 2004: The AP releases inflammatory stories (See appendices A and B) accusing NIH official Edmund Tramont of covering up severe side-effects of sdNVP during the Ugandan HIVNET 012 trial (James. 2005). It is later discovered that the problem was merely administrative and that the validity of the results from the trial remained unaffected. The Ugandan study did not cover up reports on side effects from sdNVP, as was reported (Avert. 2005). "There was never any evidence of a significant risk of side effects from only a single dose of nevirapine" (James, 2005) and:

Even if the study had been invalidated, there have since been two other major studies of single dose nevirapine, confirming its effectiveness in reducing MTCT and showing no evidence of serious side effects (Avert, 2005).

17 December 2004: Following international and local press reports on the alleged HIVNET 012 cover-up South African President Thabo Mbeki accuses the United States of using Africans as ‘guinea pigs’:

The African National Congress, the governing party in South Africa, issued an unsigned statement on 17 December, alleging that the drug was not proven to be safe but that the United States “was happy that the peoples of Africa should be used as guinea pigs” (Check, 2004).

December 2004: Respected science journals show concern in the wake of the AP reports and rally to support nevirapine:

Science magazine reports: “Much to the dismay of AIDS researchers and clinicians around the world, the Associated Press ran a series last week that has reignited debate about the safety of one of the most heralded interventions in AIDS prevention: use of the drug nevirapine to prevent HIV transmission from an infected mother to her infant” (Cohen, 2004: 2168).

Nature magazine reports that concern amongst experts and activists alike stems from the fear that the media misrepresentation of this recent nevirapine controversy will interfere with the prevention of the spread of AIDS in Africa through PMTCT:

“There are already mothers who are refusing to take nevirapine,” says Arthur Ammann, a doctor and president of Global Strategies for HIV Prevention, a non-profit organization based in San Rafael, California. “This is the most successful therapy in the entire AIDS epidemic. It should not be attacked.” (Check, 2004: 935).

Nature reports that Edmund Tramont, head of the NIH's Division of AIDS, believed that a thorough review of the study validated the conclusions that nevirapine was safe and effective, and that “scientists and advocates are standing by Tramont's conclusion, pointing out that independent trials in South Africa, Malawi and Thailand have confirmed it” (Check, 2004: 935).

May 2005: A self-published updated version of Brink’s publication *The Trouble With Nevirapine* slams the HIVNET 012 trial in the wake of the December 2004 AP reports (See Appendix D).

5 May 2005: Under pressure from the WHO’s 3 by 5 initiative, a defiant South African Minister of Health, Manto Tshabalala-Msimang, states: “It doesn't work just to dish out anti-retrovirals just because they are available....Raw garlic and a skin of the lemon -- not only do they give you a beautiful face and skin but they also protect you from disease” (CNN, 2005).

The above overview gives an idea of the extreme emotion and intricate complexities that have haunted nevirapine over the last six years. The negative statements and events in the history of the drug are based on poor science knowledge and can prove fatal when irresponsibly reported by the media because potential beneficiaries of the drug are needlessly put off:

The news story [AP reports referred to above] was unexpected because it was tied to no medical or scientific development; it went around the world immediately and no answer could catch up. It is possible that children have already been born with HIV as a result, and that many more will be infected unnecessarily (James, 2004).

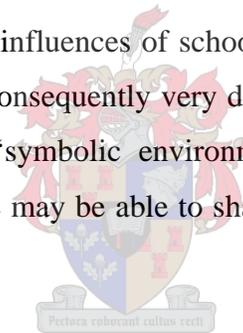
2.3 THE MEDIA

2.3.1 The power of the media

*Mass media plays a vital role in (post) modernist societies and in the surrounding global culture, which makes it a backbone of a pervasive cultural environment – the media has **influence**. This influence is greater than before, because ‘media reality’ has to a large extent taken over from ‘conceptual reality’ (De Beer, 2003: 128).*

The power of the media cannot be underestimated. The media is responsible for the communication of news to every corner of society and the public is largely dependent on mediums of mass communication for a definition of the world they inhabit. The media thus plays a pivotal role in telling us what to think about and has the capacity to guide us in our decision-making.

In a secular society, in matters of values and ideas, the mass media tend to ‘take over’ from the early influences of school, parents, religion, siblings and companions. We are consequently very dependent on the media for a large part of our wider ‘symbolic environment’ (the ‘pictures in our heads’), however much we may be able to shape our own personal vision (McQuail, 2000: 64).



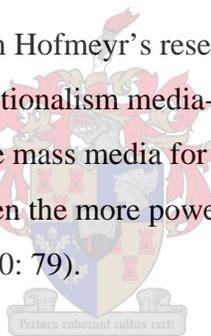
The media therefore has influence and is particularly important within the context of the management of issues which relate directly to basic human rights in developing countries such as South Africa. Nothing should stand in the way of the most basic of all human rights, the right to good health, and the South African media carries a particular responsibility here. Lynn Dalrymple, Professor of Drama at the University of Zululand and HIV/AIDS communication researcher and expert, states:

The general population in South Africa has grown up under a system that ensured that they would be poorly educated, particularly in scientific matters....Many people do not have the skills to distinguish between sensationalist reporting and the factual matter...so that everything that is read is taken as fact (Dalrymple quoted by Galloway, 2000:30).

This statement that “everything that is read is taken as fact” is supported by recent research in South Africa which suggests that the broader public “trusts the messenger”. Results from a study on the public and elite opinions on the credibility of the printed media reveal that “although there is general agreement that the print media can be more balanced in its reporting, it appears as if the vast majority in all respondent groups [including Black, White, Coloured and Indian race groups across various income brackets] do not doubt its *bona fides*” (Hofmeyr, 2003: 18).

A further and “unexpected” result from this research “is the high level of confidence registered by black respondents in the public survey (70 %) [when] the print media only caters for the interests of a small privileged minority” (Hofmeyr, 2003: 13).

It may be argued that the results from Hofmeyr’s research are not “unexpected” but rather a clear illustration of McQuail’s functionalism media-society theory which “posits that the more an audience is reliant on the mass media for information and the more a society is in a state of crisis or instability, then the more power the media are more likely to have (or be credited with)” (McQuail, 2000: 79).



The lack of adequate science education at school and the enormity of the AIDS epidemic in South Africa thus increase both the responsibility of the media in reporting on HIV/AIDS-related issues and the reliance of the public on this reporting and their belief in it.

In the light of South Africans’ high dependence on and belief in the media as a source of information (including scientific information for the understanding and betterment of public health), it is necessary to question the reliability of the media as a source of truth.

2.3.2 The reliability of the media as a reflection of reality

There can be little doubt that the media, whether moulders or mirrors of society, are the main messengers about society (Watson, 2003: 63).

If we are thus dependent on the media for an understanding of the world we live in, the least we can expect from journalists as a primary media function is an accurate reflection of reality.

The danger of the power the media exerts (especially in a developing country), however, becomes all the more apparent when a closer examination of the various roles of the media reveals that it is often the media itself which ironically stands between us and a true reflection of reality. The media as moulder of reality rather than a mirror of reality may largely go unnoticed by the public:

The rendition of reality is so convincing...because the news framed for us by the media is usually all we have to go on as a portrait of realities beyond our own environment; and partly because the news is constructed with such professional skill (Watson, 2003: 122).

Having established the influence of the media and the irony of mass communication, that although “the news convinces us that it replicates reality we have to keep in mind that it is only a version of reality” (Watson, 2003: 147), a brief overview of the various theories of the press, media roles and the news values they spawn is useful in providing a theoretical framework for a content analysis of the press.

2.3.3 The function of the media: press theories and the roles of the media

The functional approach wrestles with the problem of what mass communication should or could do in society (De Beer, 2002: 13).

A press theory is a perception about the function of the press (Fourie, 2001: 275). According to McQuail’s functionalism media-society theory “media function can refer

both to more or less objective tasks of the media (such as news or editorialising) and to purposes and utilities as perceived by a media user (such as being informed or entertained)” (McQuail, 2000: 79).

Recent revision of the theories of the press place media tasks into two categories: normative and sociological theories which deal with the subjective viewpoints of elite players (such as cabinet ministers and government officials) and the objective approach of media within society respectively. It is impossible to place any one media system into a particular category because national media systems, individual mediums and individual journalists can play a variety of roles. It is, instead, suggested that “one should rather classify the kind of arguments about media roles (functions) within the framework of a specific paradigm” (Fourie, 2001: 275).

Journalists are then perceived as working from certain paradigms including the following:

- 
- the liberal-individualist paradigm where the role of the media is to contribute to and uphold democracy
 - the social responsibility paradigm where the role of the media is to contribute to the upliftment of society and its citizens
 - the critical paradigm where the media should question prevailing and oppressive ideologies
 - the administrative paradigm where the emphasis is on the efficient transmission of reliable information to all sectors of the public
 - the cultural negotiation paradigm where the emphasis is on the rights of subcultures and a real sense of community (Fourie, 2001: 276).

Fourie explains that these paradigms lay the foundation for the roles the media can play:

- Collaborative: a role the media plays when a nation state is young and insecure. In other words to collaborate towards development ideals, nation building and

national interest. This is usually the role governments want the media to play and is the role the SA government wants the media to play

- Surveillance: the media plays an adverse role, acts as a watchdog and agenda-setter. The media exposes violations of the moral and social order. The media informs by bringing important issues to the attention of the community. This is usually the role played by the media in developed countries and often the reason for its unpopularity with governments
- Facilitative: the media seeks to create and sustain public debate. This is the essence of the public or civic journalism movement
- Critical/dialectical: journalists examine in a truly radical way the assumptions and premises of a community. The media's role is to constitute public debate about, not within, the prevailing political order (Fourie, 2001: 276).

2.3.4 News values, gatekeeping and agenda-setting

Journalistic roles carry with them their own particular set of news values and agenda-setting priorities which inevitably “construct” (distort) reality.

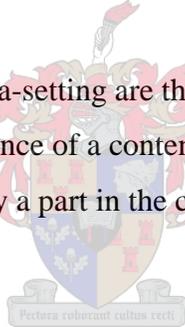
It can be argued that the British and American press, for example, perform a largely surveillance role within long-established democracies. The news values here:

tend to favour events that are about elite people, elite nations and negative happenings. Events scoring high on all these values are believed to produce most audience interest, and these values are consistent with several of the organisational and genre-related selection requirements. Thus ‘bigness’ goes with eliteness; personal actions fit the short time scale and are least ambiguous and most ‘bounded’; negative events often fit the production time schedule, are unambiguous and can be personalised (such as disasters, killings and crimes) (McQuail, 2000: 341).

News values are determined by the players in the production of news content. These players include media owners, editors, journalists and sources and all act as gatekeepers in deciding what is newsworthy and how the news should be “framed” (from which news angle the story should be presented) for the media audience. Driven by their news values the players will select (gatekeep) news items, frame the item in a particular way and thus set the agenda for the public.

The set agenda, therefore, is the final, constructed version of reality which the public reads or listens to. The mass media thus “select and call to the public’s attention both ideas and events” (De Beer, 2002: 20) and “simply by the fact of paying attention to some issues and neglecting others will have an effect on public opinion” (McQuail and Windhal, 1981: 62). The role of agenda-setting is thus central to a content analysis with an aim to understanding the effect of the media on public opinion.

News values, gatekeeping and agenda-setting are thus all inextricably linked and need careful consideration in the performance of a content analysis. These three elements and the players who implement them play a part in the construction and presentation of a distorted version of reality.



Western news values which originated in a free market system and a highly commercially competitive environment need big, bad news to command bigger headlines to sell more newspapers. Further to glossing over the good news, this type of journalism also assumes that the well-educated public is able to weed out the truth from sensationalism.

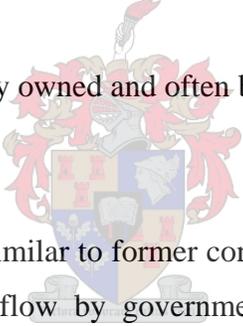
Journalists who subscribe to Western news values also focus on the elite as both objects of and sources for news. The reason for this is because “some sources are also more powerful than others or they have more bargaining power because of their status, market dominance or intrinsic market value” (Oosthuizen, 2001: 205). McQuail states that the danger then, of course, is that news “is often what prominent people say about events rather than reports of the events themselves” (Oosthuizen quoting McQuail, 2001: 205). This is how a “prestigious or authoritative source of news – for instance a political leader

or a famous academic – often acts as the first gatekeeper of news” (Oosthuizen, 2001: 204).

Gatekeeping can be defined as the process through which certain information passes a series of checkpoints (gates) before being finally accepted as news material...As a result, readers, viewers and listeners are presented with only a part of daily reality (Oosthuizen, 2001: 197).

Other media players, in addition to sources, act as gatekeepers to varying degrees. Media owners may define broad guidelines which determine the style of journalism espoused by a particular organisation but they seldom exercise direct control over the specific news stories (Oosthuizen, 2001: 197) but “media ownership and control inevitably have an influence on the distribution of information to society” (Steyn, 2002: 451).

Today the media is largely privately owned and often by multinational companies from the West. This:



has lately raised concerns similar to former concerns about the control and restriction of information flow by governments. Many fear that some countries (particularly those in new democracies), face new forms of colonialism, especially because of the involvement of multinational companies (Steyn, 2002: 451).

In other words, the Western-type news values which these multinational companies bring with them may eclipse, to a large extent, more socially responsible news values and a collaborative journalistic role which are better suited to young democratic nations.

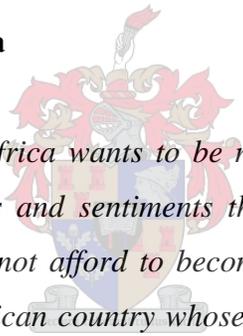
Once owners have imposed a certain type of journalism editors are expected to edit in accordance with the guidelines laid down by their board of directors. Editors’ jobs will be in jeopardy if they do not adhere to the stipulated news values of the organisation which

employs them. Editors are thus not democratic beings and hold the key to the final and most important gate which the news item may or may not pass through.

Journalists, often for reasons of survival, also gatekeep. Their needs to avoid conflict, protect their jobs and get promoted “force journalists to conform to the organisational structure that employs them” (Oosthuizen, 2001; 202).

Media players (through the inevitable practice of gatekeeping) are thus biased and so responsible for a certain “skilled construction” of reality because “the primary effect of gatekeeping... is that it changes the media’s original message in some way. What readers read in a newspaper is thus seldom an accurate reflection of reality” (Oosthuizen, 2001: 205).

2.3.5 The media in South Africa



... a quilt of what South Africa wants to be must be woven carefully by piecing together the issues and sentiments that represent the country’s values ... South Africa cannot afford to become a little United States or Little England. It is an African country whose realities and problems are very African in content and character (Diescho quoted by Steyn, 2002: 466).

In 2004 South Africa celebrated ten years of freedom, freedom from the former apartheid regime when the majority of citizens could not enjoy basic human rights such as equal access to health care, job opportunities, education and information. In spite of their new-found democracy, however, a large proportion of South Africans are still prisoners of African challenges such as poverty, ill-health and the negative mind set which accompanies these challenges.

The media, both at home and abroad, must, to a large degree, be held accountable for this negativity. Western news values (in operation in the developed world and imposed on

Africa) which tend to focus on big bad news are not wholly constructive within the context of a new and still insecure democracy such as South Africa. African disadvantages are made all the more insurmountable by an ill-fitting information system which, through Western-style agenda setting, ignores the real issues at hand with serious consequences:

As far as mass media infrastructure and its uses are concerned, the image generally held and accepted by many Africans is ... bleak. Consequently, they have a low regard for their natural abilities, mistaking their being different from Westerners as being inadequate (Mbennah, Hooyberg & Mersham, 2002: 36).

The dangers of media imperialism are thus of great concern. Africans need to understand and so be empowered to confront their “very African realities and problems”. They will only be able to do so if the media sets positive African agendas:

African organisations lack the capacity and resources to take ownership of the African story. This explains why Western powers continue to set the agenda for Africa and her people Media organisations in Africa need to urgently address the question of content and resources (Molefe, 2004: 119).

The enormous social responsibilities facing the South African media are obvious and there is no doubt that the media, without totally relinquishing its surveillance role, should be playing a more collaborative role which addresses the true needs and wants of its audience.

Recent research into the needs and wants of the South African public has been carried out by Gender Links, the media NGO based in Johannesburg. The Gender and Media Audience Study (GMAS) was completed at the end of 2004 and indicates that human interest, positive and local news stories are of most interest to audiences in South Africa.

Audiences in South Africa are not interested in violence, war, crime and bad news (Rama & Lowe Morna, 2005:74).

Democracy has brought many social, political and economic changes to South Africa but the media has yet to attain its own true democratisation which, according to the MacBride Commission 16 years ago is:

... the process whereby: a) the individual becomes an active partner and not a mere object of communication; b) the variety of messages exchanged increases; and c) the extent and quality of social representation or participation in communication is augmented (Steyn, 2002:466).

The time for some change in South African media policy is not only now nigh but long overdue: a delicate balance must be struck between the media as watchdog and nation-builder. South Africans live in a new and challenging multi-cultural democracy which demands a highly responsible and analytical approach from its media:

All of us have responsibilities towards one another. As government we expect the media to continue to keep us on our toes, as that is the conscience of our society ... Moreover, society at large – which the media constantly have to mirror, and which in turn also reflects on the media – expects them to all these things constructively, with honesty and fairness, with equality, with dignity, with impeccable intellectual finesse, and ... with the understanding that, after all, you are the South African media, writing about a South African story – a changing story, a changing environment, and inevitably a changing media (Former Gauteng premier, Tokyo Sexwale, quoted in Steyn, 2002: 466).

The section below outlines the theory of development journalism which, in spite of its nation-building attributes, must be approached with caution and implemented with balance in order to avoid the risk of “sunshine journalism”. The development theory

incorporates the right of the state “to intervene by restricting and censoring the media. State subsidies and direct control are therefore justifiable” (Fourie, 2001: 274).

Such government control would certainly compromise the media in its role of “the conscience of our society” and threaten the very ideal of democracy. Within this theoretical context, and within the context of this study, key members of the South African government would thus enjoy free political exploitation of nevirapine.

2.3.6 Development Journalism and the South African Media and Development Agency (MDDA)

Mass commercial media ...thrives on controversy and sensationalism instead of the essence of the process of communication itself (Mkonza, 2004: 117).

The unique elements related to the South African society need to be taken into account to develop a policy for the media which will best benefit the country’s unique needs and preferences” (Steyn, 2002: 466). A fresh approach to the function of mass communication in South Africa and a shift in media policy is based on the incorporation of elements of the theory of development journalism which operates from a socially responsible paradigm.

South Africa is still a fledgling democracy and faces enormous challenges amongst which is the AIDS epidemic which constantly threatens the social and economic fibre of the country. This vulnerability demands a more positive media approach such as that encouraged by development journalism which, in complete reversal to Western-style commercial journalism, caters to the true social needs of the public rather than to the free market and has as its primary function the holistic betterment of a nation.

This paradigm of social responsibility, from which development journalism operates, promotes the following communication guidelines:

- The media should accept certain responsibilities to society
- The media should fulfil their responsibilities mainly by setting professional standards with regard to the supply of information and the truth, accuracy, objectivity and balance of their reporting
- In order to be responsible, the media should apply self-regulation within the framework of the law and established institutions
- The media should avoid publishing information that can lead to crime, violence or social disruption, as well as information that can offend ethnic or religious minorities
- The media collectively should represent all social groups and reflect the diversity of society by giving people access to a variety of viewpoints and the right to react to these viewpoints
- Society is entitled to expect high professional standards and intervention is justifiable if the media fail to meet these standards (McQuail, 1987: 116 – 118).

The South African Media and Development Agency (MDDA) has been formed to encourage media diversity, especially amongst the print media. The organisation is a partnership between government, media and donors in a move to develop non-profit media for marginalised communities (Kupe, 2004: 127).

It cannot be forgotten that it is these poorer, marginalised communities which depend on information through the media for their very survival. In such communities the voices of the consumers must be heard when media agendas are being deliberated as it is the consumers themselves who can decide what is of importance to them. Participatory communication is thus at the heart of development journalism and one of the most important functions of the MDDA. Chairperson of the MDDA, Khanyi Mkoza, explains that participatory communication “defines the content of what is produced for public communication” (Mkonda, 2004:116).

Participatory communication takes into consideration the views and input of the receiver of information. It initiates an inquiry process leading to sharpened consciousness of social, human and political developments.... Participation is the key element to awakening people's desire to assess their problems critically, to ask why these problems occur and how to overcome them using their own wisdom, experience and knowledge (Mkonza, 2004: 116).

This collaborative role of the press must become a more substantial element of South African media policy if citizens are to become empowered enough to build up their spirits and their nation.

2.3.7 The media and women

*“One is not born, but rather becomes, a woman” Simone de Beauvoir,
French gender activist (Connell; 2002: 4).*

Researchers define gender as socially constructed. The distinction between male and female is seen as socially imposed by laws and ideas defining gender-appropriate behaviour. The expectation of distinct masculine and feminine behaviours are “constantly being circulated, not only by legislators but also by priests, parents, teachers, advertisers, retail mall owners, talk show hosts and disc jockeys.... Being a man or a woman, then, is not a fixed state. It is a becoming, a condition actively under construction” (Connell, 2002: 4).

This social distinction between the sexes stems from the concept of patriarchy which views the male as the dominant gender and having direct control over the passive female (Connell, 2002: 58). These values, incessantly reinforced by the many cogs within a social order, are often unthinkingly accepted by both men and women. This social construction of gender:

helps to explain why people might comply with their gendered identities, even when they propose their subordination. Moreover, it acts as a lens through which one can think about media output in relation to its gendered representations and narratives and their implications for gender justice (Strelitz & Prinsloo, 2005:120).

The media is arguably a very large social cog all too often guilty of perpetuating the false distinction between women and men. Female under-representation in the media (as editors, journalists, sources and news content) reflects the trend of socially constructed male dominance and female passivity and continues to be a barrier to the empowerment of women.

... the news generally, and international news in particular, needs to be viewed through the 'prism of gender'. When it is, we come to realise that news content and news gathering are 'gendered', with a profound and institutionalised bias towards maleness (Watson; 2003: 194).

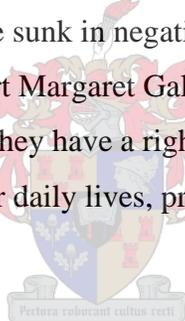
Male journalists still outnumber their female counterparts two to one (Watson, 2003: 196) and this male prevalence appears to reinforce the maxim that big, bad news sells. Papers with predominately male editors contain news with a more negative focus (Craft & Wanta, 2004). Consequently, typical Western news values such as war, shock, violence and elitism sideline women's issues:

Under the present global gender order, policymakers and journalists find it more *manly* to deal with guns, missiles, and violent conflicts than with matters like female infanticide in China, the increased trade in children in the sex markets of Manila and Bangkok in the wake of the AIDS epidemic, the impact of the intifada on Palestinian women, or the political activism of groups such as Women in Black, Israeli women who support the intifada (Watson, 2003: 195).

Stories about women such as prostitution, female circumcision, birth control and sex education “have low or no news values within the framing conventions of mainstream objective media”. They will only be found “at the margins of journalism” (Watson, 2003: 195).

Stories about women constitute news mainly under the guise of stereotyping: “women, women’s issues and problems are not newsworthy unless they can be labelled according to traditional female roles – wife, mother, daughter” (Watson, 2003: 194).

Real issues about women are therefore (to a large degree) not part of the media’s agenda setting policy. Women thus remain invisible not only to policy makers but also to other members of their communities and, worse, to themselves. Their problems are not aired nor are ways in which to deal with these issues suggested. Instead of taking action together through knowledge, they are sunk in negativity and disempowerment. As international gender and media expert Margaret Gallagher states: “Women lack access to information they need and to which they have a right, information which would help them answer questions affecting their daily lives, problems and needs” (Gallagher quoted by Strelitz & Prinsloo, 2005: 121).



Research in Southern Africa mirrors this Western media trend of “bias towards maleness”. Local research has shown that the South African media continues to perpetuate the global cycle of under-representing women and casting them in limited roles both in and out of the newsroom:

A recent study (Goga, 2000) confirmed that the ‘glass ceiling’ for women still exists in the South African media industry. Goga’s study on women as media producers in the South African media industry concluded that ‘nothing has changed’ since two initial studies in 1994 and 1998 (Rabe, 2004:138).

In 2002 Gender Links, together with the Media Institute of Southern Africa (MISA), conducted the Gender and Media Baseline Study (GMBS). Findings revealed that the editorial content of the Southern African media is gender biased:

- The highest proportion (45 %) of female media practitioners is in the TV presenter category, and lowest in the print category (22%) (Lowe Morna & Shilongo, 2004: 134)
- women constitute a mere 19 percent of news sources in South Africa (GMBS, 2003: 10 - 12)
- most stories are 'gender-blind' and fail to probe the gendered dimensions of the kinds of situations that are deemed newsworthy, whether HIV/AIDS, national budgets or war (GMBS, 2003: 10 - 12)
- women are most interested in the news topics: Health and HIV/AIDS, education and social issues but
- women constitute fewer than 30 percent and just over 20 percent respectively of news sources in these topics (GMBS, 2003: 10 - 12).

The 2004 GMAS was conducted as a sequel to the GMBS and explores the way in which the public views gender discrepancies in news content. This ground-breaking research provided evidence that

- the majority of South African women and men would find the news more interesting if the ideas and views of women were reported more often (Rama & Lowe Morna, 2005:84)
- women see education, stories about women's lives and social issues as their most important news topics (Rama & Lowe Morna, 2005: 79)
- education and social issues are amongst the top three preferred news topics for men (Rama & Lowe Morna, 2005: 79)
- most women and men perceive women in the news most often as models/beauty contestants and victims (Rama & Lowe Morna, 2005: 81)

- the majority of South African women and men would find the news more interesting if women were portrayed in a diversity of roles (Rama & Lowe Morna, 2005: 84).

The findings from the GMBS and GMSA studies confirm both the prevalence of gendered reporting in the local media and, as importantly, the public's discomfort with such reporting. The GMSA study reflects a subsequent thirst for a change in news issues on and around women, a thirst media policy makers would do well to slake as "In this [gender] dimension of our lives we face difficult practical issues about identity, social justice and even survival" (Connell, 2002: preface).

2.4 SCIENCE REPORTING

2.4.1 The importance of accurate science reporting

Misleading information is potentially dangerous: it can even cost lives
(*Social Issues Research Centre, 2001*).

This study focuses on the print media's communication of the drug nevirapine as a prevention treatment to curb the spread of HIV/AIDS. As such this research requires a satisfactory theoretical framework which both emphasises the importance of the accurate communication of science, encompassing health issues, and provides a gauge by which to measure both the value and standard of science reporting.

Science journalism poses immense challenges to the journalist. London Imperial College lecturer and BBC broadcaster Gareth Mitchell says that science writing is the most difficult form of journalism as reporters have first to understand and then explain highly complex issues to the layman in accessible terms (Mitchell, 2005).

It is, however, vital that journalists report clearly and accurately on science because:

- readers will be that much more prepared to act in their own interests (Rowan, 1990: 30)
- journalists have an obligation to explain technical ideas when their comprehension is necessary to the public's welfare (Rowan, 1990: 25)
- science/health agendas need to be consistently set by the media for the education of the public because the "mass media are important health information sources for Africans, especially for AIDS and sexually transmitted diseases" (Pratt, Ha & Pratt, 2002: 890)
- Sound science/health agendas need to be set for the benefit of public health policy makers: In sub-Saharan Africa "Independent print media are the more credible sources of information for these policy makers" (Pratt *et al*, 2002: 890).

2.4.2 The science media, agenda-setting and policy makers

It is the media that create the reality and set the public agenda, directly influencing policy decisions (Nelkin, 1995: 72).

In their news coverage the media speaks directly not only to the public but also to the policy makers whose decisions directly impact on the public. The media, through the agenda-setting process, is able to dictate which issues are worth considering and which issues are not and, as Nelkin says, "Media reports have often directly influenced public policy" (Nelkin, 1990: 74).

The ability of the media to influence public thought and policy decisions is widely acknowledged:

The media have the power to set the agenda and, in some cases, to structure people's thinking in spite of their own 'better judgement' (Kitzinger, 1993: 299).

British political theorist, Harold Laski claims that:

the real power of the press comes from its ability to surround facts by an environment of suggestion which, often half consciously, seeks its way into the minds of the reader and forms his premises for him (Laski quoted in Nelkin, 1995: 73).

If the media wields enough power to influence subconsciously and to impose opinions despite the reader's "better judgement", the role of the science journalist must be one of distinct ethical social responsibility where set agendas:

- define which issues really deserve consideration from a public perspective
- promote the most socially responsible approach to these issues.

In Africa, particularly, the role of the media in agenda-setting on health issues is of great importance as a means of curbing the spread of deadly disease:

expanding the coverage of major health issues by the media...will improve the flow of health information, increase public awareness of diseases, and help set the public health agenda for policy makers (Pratt *et al*, 2002: 890).

It is for this reason that socially responsible science journalists, setting socially responsible public agendas for all readers, need to consider their news sources very carefully. Pratt *et al* promote a "bottom up" approach based on a community power theory which encompasses the nation-building ideals of development journalism (Pratt *et al*, 2002: 891). Here the voices of the people may be used and heard as sources; sources which will subsequently set public agendas representing the real needs of the people – needs, which once aired, stand a better chance of being addressed by the policy makers.

Furthermore the media representation of these public voices humanises sickness which mobilises a community into a process of social learning. The social learning theory "emphasises the importance of examples and role models in facilitating adoption of new

practices and behaviours” (Pratt *et al*, 2002: 893). A media report about somebody who is courageously fighting a deadly disease can act as an inspiration for the community by alerting them to alternative treatments and to prevention of infection:

Through the use of the community participation model, which involves health reporting formats such as health-advice columns and biographies, popular print media can enhance the public interest in disease prevention (Pratt *et al*, 2002; 892).

A lack of disease knowledge and reporting skills, however, means “sources of information for African media may be limited to mostly authoritative and educational sources such as medical journals” (Pratt *et al*, 2002: 892). These sources, rather than promoting the needs of the people:

- set agendas which benefit the elite source (especially if the source is political in origin) rather than the general public’s needs. McQuail states, “When information is supplied to news media by sources (as much often is), then it arrives with a built-in frame which suits the purpose of the source and is unlikely to be purely objective” (McQuail, 2000; 343)
- focus on statistics, disease transmission and symptoms, which although informative, tend to be depressing, boring and lacking in the community element so essential to Africans: “Africans believe in sharing, in working together, in maintaining group harmony” (Pratt *et al*, 2002; 892).

The issue of news sources as instrumental in the agenda-setting process cannot, therefore, be glossed over within the context of science/health reporting, particularly in a country such as South Africa where there is a high level of public dependence on and trust in the media as an information source (Hofmeyr, 2003) and the country has the highest number of HIV positive individuals in the world.

A voice of authority, such as a politician, used as a source carries a lot of power within the context of a needy and trusting developing country. These sources, however, are setting their own agendas far from the interests of the general public. Furthermore, politicians are not necessarily equipped to comment on scientific fact from a sound knowledge base. As a result “the emphasis on politicians as news sources creates a situation where messages flow unedited to the public with serious consequences” (Callaghan and Schell quoted in De Wet, 2004: 103-104).

Recent research into the coverage of science and technology in the South African print media reveals that “more foreign sources and scientists (62 %) are quoted in the South African press than local sources and scientists (38%)” (Van Rooyen, 2002: 18). This fact implies that South African journalists do not trust their own scientific knowledge base and rely, instead on Western sources. This has negative consequences for the South African public as it means that international, rather than national, voices are airing opinions and appropriate local agendas are not being set by the South African media.

A high standard of science reporting in South Africa depends on the social awareness and scientific knowledge of journalists. Reporters must write in the interests of nation building, seek out the voices of the general public and so set socially appropriate and national public agendas because, quite simply, “media influence the elite group and policy makers in Africa” (Pratt *et al*, 2002: 892).

2.4.3 The nature of science reporting within a commercial news framework

There is an emphasis on statistics and what politicians and others say about AIDS, but little genuine science or in-depth educational reporting. Such articles generally have lower news value and, when space becomes a problem, are probably dropped for something more ‘spicy’ or current (Galloway; 2001: 29).

Having established the importance of good science reporting for the public and influential policy makers alike, it is now time to consider how science is commonly portrayed in the media.

Van Rooyen reveals that the coverage of science and technology in South African print media is inadequate with only 1.8 percent of editorial space dedicated to the topic (Van Rooyen, 2002: 13) and Galloway states that “there is still a dearth of in-depth science reporting in South African newspapers” (Galloway, 2001: 52).

A major reason for this unsatisfactory state of affairs is the paradoxical nature of science writing within the context of commercial media communication. Science journalism, more than any other form of journalism, should be based on reliable facts and knowledge; be free of bias and represent the needs of the public. Science journalism must be a true reflection of reality and never provide a constructed version of it because lives may depend on the information conveyed.

Any news story, however, in order to sell papers, relies on varying degrees of bad news, shock and sensationalism. This is because readers want a story which will thrill and amuse instead of bore and confuse. The science story, dangerously and sadly, is not exempt from this reality-distorting element. *Guardian* science editor, Tim Radford explains:

Science reporters in Britain and in the United States do not even try to report science, not in the sense of science as a series of systematic, one-step-at-a-time advances in knowledge on a huge front. They look instead for stories within the field of science....In a daily paper, science reporters compete with other reporters not just for space but, more important, for readers (Radford: 2004: 300).

Former editor of the *New England Journal of Medicine*, Arnold Relman, puts it simply: “The press, the media in general, are much more interested in the story, the news, than in the facts” (Relman quoted in Nelkin, 1995: 146).

Commercial news values thus dictate a tone, a choice of sources and an agenda-setting process which do not marry well with science reporting. The pure facts of a science news report are easily compromised in the ceaseless daily battle of commercial media. Fierce competition for readership tempts reporters to saturate their science stories with literary and journalistic devices such as metaphors, pinning news onto dramatic key events and presenting news in a salient frame (news angle) which grabs the reader. All these devices rob a journalist of total objectivity and instil bias in a story. Most importantly these techniques have a powerful effect on the media audience through the agendas they set and by reinforcing these agendas through powerful imagery and a sense of drama.

Metaphors are a useful tool both as a means of explaining difficult scientific phenomena through imagery and analogy (and as such are essential to science reporting) and dressing up facts to allure the reader (and as such should be used discerningly by the journalist):

Metaphors affect the ways we perceive, think, and act, for they structure our understanding of events, convey emotions and attitudes, and allow us to construct elaborate concepts about public issues (Nelkin, 1995: 11).

Metaphors have the ability to drown the pure facts of the story in a wash of powerful language which may have the effect of brainwashing the reader into adopting an imposed opinion. This is particularly true of science journalism where metaphors are relied on heavily by writers and readers to allure and explain and, in so doing, influence:

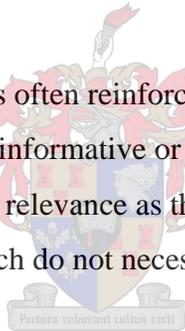
“Metaphors in science journalism cluster and reinforce one another, creating powerful images that have strategic policy implications” (Nelkin, 1995; 73).

Science stories are often “tailored” to fit in with certain commercial news values (such as elitism, drama or shock) by being pinned onto key events which carry these values with them. McQuail explains that the key event:

refers to the kind of event that becomes a big news story not only because of scale, unexpectedness and dramatic quality, but because of some unusual degree of public resonance and significance in symbolising some deeper public crisis or anxiety (McQuail, 2000: 342).

The key event thus trails in its wake a “wave of reporting that is quite disproportionate to the reality of occurrence of events” (McQuail, 2000: 342). The public, as a result, experience a distorted version of reality which is especially alarming in the case of science and health reporting.

The selling value of a science story is often reinforced by being placed in a political or economic frame rather than a purely informative or educational frame. Here, once again, the science story loses reliability and relevance as the media sacrifices scientific accuracy for selling spin and sets agendas which do not necessarily reflect the voices or the needs of the public. McQuail explains:



Framing is a way of giving some interpretation to isolated items of fact. It is almost unavoidable for journalists to do this and in so doing departing from pure ‘objectivity’ and introducing some (albeit unintended) bias (McQuail, 2000: 343).

Science stories are often presented within a risk frame because risks are scary and scary sells. As *British Medical Journal* assistant editor, Graham Easton, points out, “Human nature dictates that the best stories...are surprising, unusual, dramatic, or emotive and usually personal – all key ingredients of stories about, for example, killer bugs, the pill scare...” (Easton, 2003: 756).

Journalists must certainly report on risk as the public needs to be alerted to issues which have the potential to harm but, just as importantly, journalists must report on risk responsibly by setting out the real risks and so provide more perspective than drama. Poor risk communication can have huge human cost as seen by the unfounded Pill scare in Britain in 1995 when irresponsible risk reporting contributed to thousands of unwanted pregnancies and more than 29 thousand abortions (SIRC, 2001: 6).

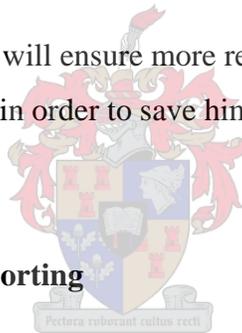
Fright factors come into play in science reporting when controversial issues become a news value. Dr. Peter Bennett of the British Department of Health states that risks are generally more worrying (and less acceptable) if perceived:

- to be **involuntary** (exposure to pollution) rather than voluntary (smoking)
- as **inequitably distributed** (some benefit while other suffer the consequences)
- as **inescapable** by taking personal precautions
- to arise from an **unfamiliar or novel** source
- to result from **man-made, rather than natural** sources
- to cause **hidden and irreversible** damage
- to pose some particular danger to **small children or pregnant women** or more generally to **future generations**
- to threaten a form of death (or illness/injury) arousing **particular dread**
- to damage **identifiable rather than anonymous victims**
- to be **poorly understood by science**
- as subject to **contradictory statements** from responsible sources (or, even worse, from the same source) (Bennett, undated: 5).

When reporting on risks journalists must employ certain guidelines which take into consideration the effect on the reader of the fright factors listed above. Bennett suggests a risk management checklist:

- **Anticipate public impact:** have possible economic, social and political consequences been taken into consideration? Irresponsibly communicated risks can cause unwanted changes in public behaviour
- Always quote the **baseline** risk (do not dumb down information): Journalists must quote the pre-existing risk and allow the reader to judge the significance of the findings
- Employ clear **risk comparisons** which relate to the daily lives of readers (this may help with the interpretation of confusing percentages or odds ratios)
- Do not juxtapose data on **voluntary and involuntary risk**
- Acknowledge **uncertainties in scientific assessments**
- Ensure that the emotional tone is appropriate to the **values of the audience** (Bennett, undated: 5)

Adherence to the guidelines above will ensure more responsible risk reporting which “guides” the reaction of the reader in order to save him/her a lot of unnecessary angst over a “juicy” risk report.



2.4.4 Guidelines for science reporting

...media coverage of scientific matters should be governed by a Code of Practice which stipulates that scientific stories should be factually accurate. Breaches of the Code of Practice should be referred to the Press Complaints Commission (House of Commons Science and Technology Committee, 1999 in SIRC, 2001: 3).

The challenges facing science journalists in a commercial news environment are immense. As hard as it is, however, for science reporters to explain complex issues in a compelling manner, without sacrificing any truthful fact, it is vital that they do so. If reporters are able to attain and maintain such high ethical standards of health journalism, the most important component of the media communication equation, the public, will be able to act responsibly and safely in their own interests:

Good reporting can enhance the public's ability to evaluate science policy issues and the individual's ability to make rational personal choices; poor reporting can mislead and disempower a public that is increasingly affected by science and technology and by decisions determined by technical expertise (Nelkin, 1995: 2).

The Social Issues Research Centre (SIRC), the Royal Institution of Great Britain (RI) and the Royal Society (RS) have presented the following science reporting guidelines for print and broadcast media in an effort to quell "the negative impact of what are viewed as unjustified 'scare stories' and those which offer false hopes to the seriously ill" (SIRC, 2001: 3).

These organisations suggest that journalists, when covering science/health issues, consider the following:

- 
- Credibility of sources (have the findings been published in a peer-reviewed science or health journal)
 - Procedures and methods (were the research methods appropriate and what do other science professionals think of the methods)
 - Findings and conclusions (is this really a 'breakthrough')
 - The significance of findings (are the findings: preliminary or inconclusive; differ markedly from previous studies; contradict mainstream scientific opinion; based on small or unrepresentative samples; generalise to humans from animal studies)
 - Communicating risk (have researchers been asked 'how safe is it' instead of "is it safe?"; are the risks expressed in absolute as well as relative terms; can the risk be compared with anything else)
 - Anticipating impact (will the report cause undue anxiety or optimism among readers; have important caveats been properly included)
 - The role of specialist correspondents and editors (what do specialist journalists think about the report)

- The role of sub-editors (is the headline a fair reflection of the report; is the caption a fair reflection of the report)
- Expert contacts (what do other professionals in the field think of the research)

Guidelines cannot ensure error-free copy but they should increase accuracy, balance and minimise the potential for misleading conclusions (SIRC, 2001: 4 – 7).

2.5 REPORTING ETHICALLY ON HIV/AIDS AND RELATED ISSUES

2.5.1 Ethical guidelines for reporting on HIV/AIDS

...Whether or not they actively seek to do so, the media either fuel the epidemic through sensationalism and poor or unethical reporting, or help to restrain it by promoting information, understanding and behaviour change. The media shape attitudes, influence national agenda for good or for ill; it educates or misinforms; it investigates or ignores malpractice; and it raises or ignores questions of cultural values that lie behind the epidemic... (Martin Foreman, former director of London-based Panos Institute's Global AIDS programme, quoted by Oriang, 2004).



Guidelines in reporting ethically on HIV/AIDS is an important criterion within this theoretical framework as the media communication of nevirapine as a treatment for AIDS, falls into this context.

Within this context all journalists need to be sensitive to the fact that their words (written or spoken) have very real consequences in people's lives. In the words of Tim Radford: "When you sit down to write, there is only one person who matters in your life. This is someone you will never meet, called a reader" (Radford, undated: 1).

Radford's philosophy is all the more important to those reporting on AIDS issues because the media is the source from which most people glean their information on AIDS. It is therefore "vital that media workers stay abreast of [AIDS] developments and convey them accurately" (Ansell, 2005; 210).

Yet it would appear that journalists in South Africa continue to shirk their social responsibilities in writing accurately and clearly on HIV/AIDS issues for the public. Journalist and author, Gwen Ansell, states that “reporting on HIV and AIDS in southern Africa today still reflects a range of practices that qualify simply as bad and unethical journalism” (Ansell, 2005: 210). This recent observation suggests that matters have not improved since Galloway’s research four years ago which found that there was a need to report on HIV and AIDS with “increased urgency, sensitivity, passion, compassion and commitment to high standards” (Galloway, 2001; 140).

The words of South African journalists on the epidemic need to be weighted with social responsibility due to the graveness of AIDS in this country, the dependence of the public and policy makers on the media for information on health issues, gender inequality within the cultural context and the stigma attached to the disease: “It is vital that AIDS is publicised as widely as possible so that people come to understand it is just another illness” (Nelson Mandela quoted in Ansell, 2005: 210).

Reporting on AIDS in South Africa provides a classic opportunity for the implementation of the ‘bottom-up’ approach by the media which:

- Voices the opinions of the public through relying on this sector as providing the socially appropriate sources
- Humanises AIDS by giving it the faces of those who are HIV positive and who are approaching their illness as a manageable chronic condition
- Promotes a positive and accepting public spirit
- Encourages social learning
- Empowers not disempowers.

This approach incorporates the attributes of development journalism (discussed earlier in this thesis) which sets socially appropriate nation-building agendas for developing countries; agendas which will promote realistic public health policies, instil power and positive attitudes through knowledge and dispel stereotypes and stigma through the representation of the voices of the people rather than of the elite authority.

Ansell offers up-to-date guidelines on HIV/AIDS reporting for South African journalists which take into consideration the social, cultural and historical peculiarities of this developing country:

- Describe and explain: do not use HIV/AIDS as a vehicle for reporter bias/opinion or propaganda
- Give balanced reports of both sides of the story
- Death is not the only 'acceptable' news story about AIDS: consider stories about HIV + people who are surviving and living their lives
- Use a wide source base: do not take the easy route information by using official spokesmen for government and drug companies
- Do not dumb down arguments: for example - differentiate clearly between HIV and AIDS: by glossing over the differences between being HIV positive and 'dying of AIDS', journalists leave no room for survival strategies
- Avoid sensational "horror" reporting which only promotes stigma and despair [AIDS is a classic candidate for fright facta risk reporting]
- Contextualise information socially, economically, technically and historically so that readers are not misled
- Do not stereotype and promote stigma
- Provide accurate and up-to-date information (AIDS treatment is constantly changing and journalists must keep track – the Web is a useful tool for new information)
- Consider the source of information carefully; what position does the author promote, is the research thorough and peer-reviewed
- Make medical jargon accessible to the reader
- Be gender-sensitive
- Use an affirmative, positive writing style which encourages readers rather than bullies or scares them
- Reports should be non-discriminatory: people living with HIV or AIDS are not a danger to others and they are not victims. If your stories create stigma or provide

grounds for discrimination, you're contributing to atrocities like the murder of women who declare their status

- Report on alleged cures for AIDS without endorsing these claims and get impartial scientific comment on such claims
- Report responsibly on statistics: understand how statistics and averages work
- Build a community aspect into reporting: the epidemic has dramatically different impacts upon different people who have dramatically different capacities for response. Reporting on AIDS should reflect how different parts of our society respond differently to the illness
- Be sensitive to the fact that many women in South Africa, due to the predominant patriarchal social belief system, are disempowered and unable to negotiate safe sex: do not, therefore, base reports on the assumption that women can control when and how they have sex
- Understand how the economy works and where to find data on health budgets
- Ask official sources for concrete financial information
- Ask about assumptions and alternatives when interviewing about policy decisions
- Recognise that trade agreements about issues like drug imports represent huge amounts of money; ask: "Who benefits? Who will suffer? – long-term as well as short-term"

(Ansell, 2005: 210 – 222).

2.6 OVERVIEW OF THE MAIN FINDINGS IN THE LITERATURE REVIEW

A summary of the main conclusions drawn from the literature review is essential in highlighting the main issues which form part of the following empirical study.

Recent AIDS statistics for South Africa reveal that the epidemic is growing. Further to this, for cultural and simple biological reasons, greater numbers of women are becoming infected by the disease.

The growing epidemic and the particular vulnerability of women and young girls in the face of the disease reinforce the special role the drug nevirapine can play in the prevention of the vertical transmission of HIV in RPS. The emphasis on nevirapine as a positive treatment regimen, however, has often been sabotaged by dissident activity from both AIDS dissidents and South African politicians alike.

The international media has recently transgressed in its portrayal of nevirapine by sending out dangerously mixed messages to the public about the drug. This may be due to a combination of writing on AIDS issues from: a commercial news perspective and thus lapsing into sensationalist reporting; or from an inadequate knowledge base on the drug. As a result of this irresponsible media coverage, there is confusion amongst AIDS patients who are showing reluctance to use nevirapine to prevent the vertical transmission of HIV (Check, 2004: 935).

This public reaction is not surprising considering the power the media yields. That the media has influence, as an often trusted messenger, is an established fact; that this influence is of particular importance in sub-Saharan Africa, where the scientifically uneducated public in the midst of a health crisis, relies on news for information (Hofmeyr, 2003: 18) is pivotal to this study.

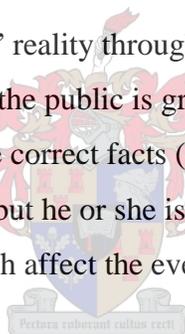
Also pivotal to this study is the fact that the media influences policy makers: “It is the media that create the reality and set the public agenda, directly influencing policy decisions” (Nelkin, 1995: 72). It is important to note, therefore, that the words of journalists quite simply create the worlds we live in because media reports not only “explain” our worlds for us, but influence the policy makers who define the laws by which we live.

The concept of public trust in the media as a reliable source of information is alarming when mass communication experts warn of the underlying distortion of reality in news reports due to reporter bias:

The media are themselves an institution with their own goals, rules, conventions and mechanisms of control. Their objectives do not necessarily coincide with the primary goals of the society, nor even with the aim of relaying some objective ‘truth’ about reality (McQuail, 2000: 67).

This reporter bias and unpure version of the truth largely goes unnoticed because the news is presented with a high level of professional skill which renders it believable (Watson, 2003: 122). In South Africa media audiences are even more likely to believe in a media-constructed reality because the general public, through a lack of education, is unable to decipher fact from fallacy and believes pretty much everything they read (Dalrymple, 2001: 30).

Within the context of a “constructed” reality through the highly skilled stroke of a pen, the science writer’s responsibility to the public is great. Not only is the journalist directly responsible for feeding the public the correct facts (enabling them to make informed decisions on issues of life or death), but he or she is a vital source of information for the policy makers who set the rules which affect the every-day lives of ordinary people.



In South Africa, a developing nation fighting a disease which causes the most deaths amongst the optimal working age group (25 to 49 years of age), media policy needs to urgently address the needs of the ordinary people. Change in the newsroom is required to encourage journalists, amongst them health/science writers to adopt a more balanced social responsibility role (Steyn, 2002: 466).

Commercial news values suffocate the development function of the media (Mkonza, 2004: 117), especially within the context of science reporting. A journalist committed to commercial news values, will tailor a piece of scientific news by draping it in metaphor; pinning it to a salient key event or presenting it within a sellable commercial news frame. This process both compromises pure scientific fact and sets an agenda (perhaps a political one) which does not reflect the real needs of the public (Nelkin, 1995: 72).

It is the theory of development journalism, rather, which caters to the nation in need of positive building up of body and spirit. Research shows, moreover, that the South African public is ready for a fresh news agenda, removed from the commercially-driven Western media theory that “bad news sells” (Rama & Lowe Morna, 2005:74).

A journalist committed to social news values, promoted by the theory of development journalism, will inform rather than disinform; use appropriate sources without political agendas and draw together and empower communities through the accurate and relevant release of information through the media.

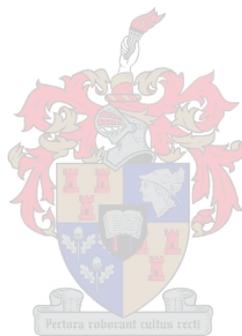
The dissemination of socially relevant and accurate information to the public through the voices (as news sources) of the community (including doctors, researchers and ordinary people alike), would appear, in theory, to be highly compatible with responsible science/health reporting, and more specifically, reporting on AIDS issues. Social news values, in direct contrast to commercial news values, will allow the flow of accurate, scientifically sound and clear messages to the public.

The journalist’s socially responsible approach will, furthermore, help to dispel the crippling stigma surrounding AIDS in many South African communities. The “bottom up” approach of development journalism ensures that the voice of the community rings loud and clear through the media. Within the AIDS context this can be beneficial in giving the disease a human face as the AIDS-affected population speak out positively about their experiences, so that AIDS is recognised as just another illness and not a curse to be socially feared and shunned. It is here that the media can play a constructive role in promoting a social learning process which will help curb the spread of the disease (Pratt, 2002: 893).

A key consideration in this study is the media representation of women’s voices with regard to nevirapine as an effective ARV. Research has proved that women are drastically under-represented in the media (GMBS, 2003). This disturbing trend can be

reversed by the enforcement of a collaborative newsroom philosophy advocating diversity and the representation of minority groups (Kupe, 2004: 127). Studies show, moreover, that the majority of South African media audiences want the opinions of women voiced more extensively through the media (Rama & Lowe Morna, 2005).

The above extrapolations have been drawn from the main body of the literature review to focus the ensuing study. These key findings form the foundation which dictates the form and content of this research. From here on this study aims to answer the research questions prompted by the theories and findings identified in the above review.



CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

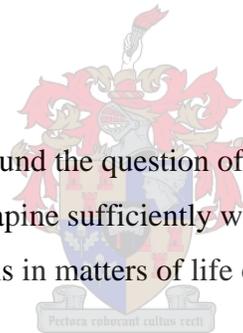
3.1 HYPOTHESES, CONCEPTUALISATION, DEFINITIONS AND KEY VARIABLES

This chapter documents the design and methodology used during the research fieldwork. The research problem is clearly defined and focused by the formulation of research questions. Expectations substantiated by the preceding literature review are discussed. Data collection methods used to explore these expectations are explained in detail, as are the key variables.

3.1.1 Research problem, expectations and questions

The research problem

The research problem revolves around the question of whether or not the Western Cape print media currently covers nevirapine sufficiently well to inform and empower the public in making the right decisions in matters of life or death.



The overarching expectation of this study is that the South African public has a negative experience of nevirapine reportage from the print media which inhibits informed decision making. This expectation was arrived at through a literature review of established theories and research relevant to the research problem. The texts reviewed consisted of information pertaining to:

- science reporting with a focus on HIV/AIDS news coverage
- media theory and function
- correct clinical facts of nevirapine

Expectations

The literature review provided a guide from which the researcher was able to establish the following expectations:

- South African print journalists are not aware of the vast responsibility they carry in nevirapine reportage: they do not “see” the individuals they are reporting to
- Clear science/health communication on nevirapine is sidelined by commercial news values
- Public health agendas are sidelined by political agenda setting through the use of the voice of political authority as a source
- Science reporting on nevirapine, when it does occur, is unbalanced, inaccurate and unclear
- Ethical guidelines in reporting on nevirapine are not adhered to
- Women’s voices are largely silent as sources in nevirapine reporting.

Research questions

Research questions both focus the research problem and provide the basis from which to embark on the methods of observation. The questions here are empirical and address the reality of media content and influence in a holistic manner from an exploratory, descriptive, causal and evaluative angle (Mouton, 2001: 53).

The research questions below offer opportunities for the positive or negative categorisation of all units of analysis under study:

- Does the science reporting follow an analytical, science-like approach, taking into consideration science writing guidelines such as those suggested by the SIRC
- Is the science reporting clear and accurate
- Do the journalists have an in-depth knowledge of the clinical features and benefits of nevirapine
- Who are the information sources in the reports (women, politicians, scientists, activists)

- Which agendas do the reports set (political, informative, scientific or educational)
- Does the reporting on nevirapine follow ethical guidelines on HIV/AIDS reporting
- Does the public understand the benefits of nevirapine treatment
- Is the public correctly informed on the toxicity and resistance of nevirapine
- Do the reports exacerbate the fear of the AIDS stigma
- Do the reports victimise and so disempower the public
- Are the reports socially, culturally and gender sensitive, respecting the historically different backgrounds of readers who, through the patriarchal belief system, have been disempowered within society and relationships and are limited in their choices for dealing with the impact of AIDS and treatment possibilities

3.1.2 The key variables

A reliable interpretation of the Western Cape public's experience of nevirapine reporting in three local newspapers is dependent upon the observation of variables within various units of analysis relevant to this study.

“Units of analysis are the people, groups (i.e. families), organisations or things (i.e. social artifacts such as films, books, newspapers etc.), or anything else that has some relevance, whose characteristics we wish to observe, describe and explain” (Lemon, 1997: 39). The three units of analysis pertinent to this research are:

- selected newspapers/news reports
- media practitioners
- Aids experts and the AIDS-affected public

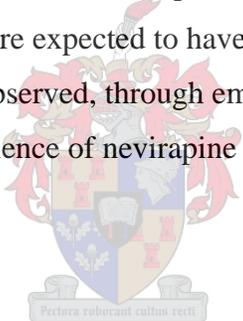
Wimmer and Dominick define a variable as “a characteristic or attribute of a person, place, or object you are studying” (Lemon, 1997: 39).

There are thus three variables relevant to this research:

- the direction of nevirapine reportage in selected print media
- the attitude of editors and journalists to nevirapine
- the experience of ordinary citizens of nevirapine reportage

The relationship between these three variables is the fulcrum upon which the answer to the research question depends. The public's experience of nevirapine reportage can be defined as the dependent variable which forms the focus of this study. It is the variable which the research attempts to describe and explain. It is referred to as the dependent variable because it is reliant on the independent variables for its explanation (Lemon, 1997: 39).

The independent variables (the attitude of media practitioners to nevirapine and the direction of nevirapine reportage) are expected to have an effect on the dependent variable described above and are observed, through empirical study, to explain why/account for the public's experience of nevirapine reportage.



3.1.3 Key variables defined

Definitions of the key concepts upon which the research outcome hinges are important as they orientate the reader and provide boundaries within which the researcher can operate, confident in the knowledge that she will not stray from the issues at hand.

An expansion of the key variables outlined above are as follows:

- The 'negative', 'neutral' and 'positive' **direction** of nevirapine reportage
- Media practitioner **attitude** to and **portrayal** of nevirapine: what is it based on?
- Public **experience** of nevirapine reportage. Are the right messages getting to the right people?

The direction of media content is accessed in the first research phase of this study through a content analysis. Content analysis “can be most productive when it is able to show direction – or the lack of it” (Budd, 1967: 50).

It is important to point out that an element of subjectivity unavoidably exists in the definition of direction because it is the researcher who provides this definition based on a personal opinion of preliminary reading and an independent knowledge of the issue under research. On the other hand, however, “although such definitions are somewhat subjective, they tell the reader of the study how the final figures were obtained” (Budd, 1967: 51).

The direction classification (negative, positive or neutral) is based on a primary review of the material selected for study; a knowledge of outside events and expected audience responses (Budd, 1965: 51). A directional coding scheme evolved from these elements, allowing the researcher to define nevirapine reportage direction as follows:

Negative: those items which misrepresent nevirapine and related issues within a national context and so potentially exacerbate the local AIDS epidemic. Negativity will be judged on the basis of socially irresponsible and insensitive reporting which does not take into consideration the cultural, social and historical complexities and challenges of South African day to day living. Such reporting incorporates:

- Incorrect and unclear scientific facts pertaining to nevirapine as both a drug (with emphasis on resistance and toxicity) and as a treatment
- Sensationalising of drug toxicity and resistance (here a distinction is drawn between straightforward incorrect scientific fact and cashing in on the fear factor to draw readers)
- The depiction of traditional medicine, vitamins and vegetables as a *preferred* treatment or, worse, as a “cure” rather than nevirapine as an effective treatment resource (it is important to note here that traditional ‘mutis’ have their place in

- perhaps alleviating symptoms but cannot take the place of nevirapine and should always be used in conjunction with nevirapine only with the approval of a doctor)
- The perpetuation of a sense of helplessness and disempowerment through stories relating ‘how it went wrong’ with nevirapine
 - Civil disruption and mixed messages: reports of disagreement on nevirapine as an effective AIDS treatment from voices of authority (politicians in particular)
 - Items which set political agendas while reporting on nevirapine
 - Items which impose a Western opinion without taking into consideration the cultural complexities (and subsequent gender challenges) of South African society.

Positive: those items which depict nevirapine in such a way as to motivate public acceptance, trust and use of the drug in the fight against AIDS. Positivism will be judged on the basis of socially responsible and, to a large degree, gender sensitive reporting which takes into consideration the fact that the majority of South African women are not empowered enough, within the patriarchal belief system, to make informed decisions on nevirapine treatment. Such reporting incorporates:

- Correct and accessible (easily understood by the South African layperson) scientific facts pertaining to nevirapine as both a drug and a treatment
- Reports which quote scientific/medical sources (as opposed to political sources) when reporting on the clinical aspects of nevirapine
- Balanced scientific reporting which responsibly outlines risk while at the same time promoting the drug’s benefits
- The use of voices of authority (political and medical) to spread the benefits of nevirapine
- The use of female voices in the community (which speak directly to the other women ‘out there’) as sources for public comments on an issue which directly affects women

- Items which relate individual success stories of nevirapine, stories which strengthen female resolve in the face of the epidemic and dispel stigma (the more people speak out the more stigma becomes a lesser issue)
- Items which set educational or scientifically clear agendas for a South African public.

Neutral: Those items which cannot be placed as either negative or positive due to their uncontroversial nature.

The second phase of the research process relates to the attitude of media practitioners towards nevirapine. The definition of the “attitude” of media practitioners, including editors and journalists, can be based on the following criteria:

- Extent of knowledge of the scientific clinical facts of nevirapine
- Extent of knowledge of nevirapine treatment regimens
- Ability to transmit scientific knowledge clearly and accurately to the public
- Desire to transmit scientific information/ Nevirapine issues accurately without interference or bias from commercial/Western news values
- Resource to sources in the reporting of nevirapine
- Perception of the role of the media within South African society
- News value focus: which determines what kind of event will be reported and how it will be reported, and, by implication, about what will be neglected (McQuail, 2000: 343)
- Degree of sensitivity to and awareness of South African cultural and historical challenges (including awareness of majority of Africans’ reliance on the media, due to an inadequate scholastic education, as a reliable source of information)
- Degree of sensitivity to gender issues surrounding nevirapine.

The attitude of the journalist or editor, is determined à propos the above criteria and subsequently defined as serious, committed and socially responsible or superficial and socially irresponsible.

The third and final phase of the research process involves interviews with doctors who work with HIV positive women and a focus group study of the public (HIV positive mothers) in order to determine the public experience of nevirapine reportage.

“Experience” may be defined as how the public perceives nevirapine based on what is reported in the print media. The perception may be either negative or positive and is judged on the basis of the following viewpoints:

- That the risks of nevirapine override the desire to use the drug as a treatment
- The scientific jargon around the drug is not understandable and creates uncertainty
- Treatment outlines are unclear and do not encourage use of the drug
- There is not enough nevirapine coverage to instil familiarity and trust in the drug – potential users do not know anything about the drug
- The public trusts the drug as a way to prevent PMTCT
- Women feel as though they are being adequately addressed by the media within the context of nevirapine issues
- The public feels, as media sources, that their views and concerns on nevirapine are fairly and accurately reported by the print media.

3.2 ISSUES OF MEASUREMENT

A strong argument for how the public experiences nevirapine reportage depends on structured and reliable instruments used in the measurement of the key variables.

Each measuring instrument used in this study is individually discussed a propos the data collection method to which it pertains. As such a coding sheet and questionnaires are defined within the context of the functions of a content analysis, in-depth interviews and a focus group study respectively.

3.2.1 A coding sheet for content analysis

News messages carried within a text are both manifest (that which the communicator overtly intends the reader to grasp) and latent (hidden messages which filter through to the reader via the communicator's bias):

It may not go too far to say that the most interesting aspects of media content are not the overt messages, but the many more or less concealed and uncertain meanings that are present in media texts (McQuail, 2000: 304).

A content analysis, as a research tool, can be applied to media texts to establish both manifest and latent messages. There is a widespread tendency “to interpret content in terms of its *probable* [italics own] consequences, whether good or bad, intended or unintended. Attention is directed both at overt intentions of media and at unintended bias and hidden ideology” (McQuail, 2000: 305).

As media messages become apparent through a content analysis of news texts, the researcher gains perception into the possible effects of their communication. The analysis of media content contributes to an understanding of the audience's perception of news by offering techniques for coping with the interpretation of news messages by the public (McQuail, 2000: 306). Communication researcher Richard Budd states succinctly that content analysis is a “systematic technique for analysing message content and message handling” (Budd, 1967: 2).

Having defined the functions of a content analysis it is now appropriate to introduce the instrument used to measure the key variables. The instrument here is a coding sheet.

The manifest and latent messages in a text are unlocked through a coding process: “To conduct a content analysis on a text, the text is coded, or broken down, into manageable categories on a variety of levels – word, word sense, phrase, sentence or theme” (Palmquist, undated). Budd states:

No content analysis is better than its categories, for a system or set of categories is, in essence, a conceptual scheme. Where categories are in fact variables; they are linked to the problem and the theories on which the research is based (Budd, 1967: 39).

Once the categories have been defined they must be ‘sorted’ into a coherent system to facilitate observation: “a scheme must be devised for recording observations so that the data can be analysed” (Budd, 1967: 31).

The categorisation of media reports on nevirapine is aided by a coding sheet modelled on the example used by Robert Donohew in his doctoral dissertation, *Publisher Attitude and Community Conditions as Factors in Newspaper Coverage of a Social Welfare Issue*, from the University of Iowa in 1965 (Budd, 1967: 40).

Motivation for selecting Donohew’s model as a guide in a coding sheet construction stems from the essential similarity in what is being measured in both Donahew’s study and the author’s own: the direction of newspaper content with regard to a particular issue and the attitude of media practitioners with regard to that issue.

The coding sheet constructed for the purposes of this study (see appendix E) consists of categories spawned by the research questions in section 3.1.1 as “the answers you seek should be the first determinant of the system of categories you use, because categories are the counterparts of the questions normally asked in any research study” (Budd, 1967: 42). By using the research questions (which focus the research problem itself) as a guide for category definition, the coding sheet as a whole is guaranteed to yield information demanded by the research problem.

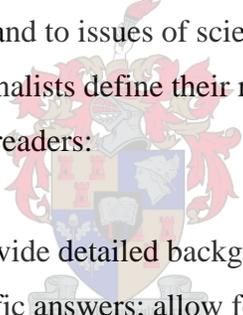
A preliminary reading of newspaper reports on nevirapine, prompted by the grounded theory approach (which allows themes to surface through observation) revealed that the content would follow one of three directions: positive, negative or neutral. The categories

in the coding sheet were therefore carefully chosen to reflect possible content direction, based on the definition of direction in section 3.1.3, and, as such, have a high probability of answering the research questions and testing the basic research expectations.

3.2.2 In-depth interviews for media practitioners

Central to the concept that the essence of journalism is communication is the relationship between the communicator (the reporter) and the receiver of information (the public).

In-depth interviews will be used in this phase of the study as instruments of measurement to determine how media practitioners interpret the role they play in communicating health issues, such as nevirapine, to the public. The interviews will be used as a tool to explain the content direction of media reports on nevirapine, gain insight into editors' and journalists' attitudes to nevirapine and to issues of science reporting. The interviews will thus give an indication of how journalists define their role in society and how seriously and sensitively they consider their readers:



In-depth interviews can provide detailed background about the reasons why participants give specific answers; allow for observations of participants' nonverbal behaviour; and can provide extensive data concerning participants' opinions, recollections, values, motivations and feelings (Pitout, 1997: 112).

The construction of the questions for the interviews takes into consideration the definition of the key concept of reporter "attitude" to nevirapine in section 3.1.3 above. This ensures that the interviewees will yield information pertinent to the research questions upon which the study is based.

Two types of interview can be conducted to elicit information from media practitioners: cultural interviews and topical interviews:

Cultural interviews are about learning how people see, understand, and interpret their world. In cultural interviews, the researcher spends most of the time listening to what people say rather than posing detailed and focused questions... By contrast topical interviews are focused on subjects that the interviewer has chosen, involve more active questioning and rapid exchanges, and are more concerned with matters of fact and less concerned with eliciting shades of meaning than cultural interviews are (Rubin & Rubin, 1995: 195).

This study combines these two forms of interview “because they share the underlying assumptions that guide all qualitative interviewing” (Rubin & Rubin, 1995: 35).

The questions for editors are attached in appendix F and those for journalists are attached in appendix G. It is important to note here that these questions provide a basic structure from which the researcher can operate: interviews can be fluid in nature and the interviewer may adapt the questions, by adding or omitting questions, according to the flow of the interview: “This preliminary analysis tells you how to redesign your questions to focus in on central themes as you continue interviewing” (Rubin & Rubin, 1995: 226).

3.2.3 Interviews with AIDS specialists and the public focus group

The interviews with the AIDS specialists test the relationship between the communicator and the public as well as giving a scientific take on the quality of health reporting on nevirapine.

Once again these interviews are cultural and topical in nature and will be analysed to see whether or not they verify the findings of the previous two phases of field research.

The focus group interviews explore first-hand the way in which the public experiences nevirapine reportage. This final phase of the field research both validates and contributes to the researcher's suggestions of how the media audience perceives nevirapine.

It is vital that the interviews with HIV positive mothers and those doctors who treat these women are conducted because this study would be incomplete without it as "content on its own cannot be taken as evidence of effect" (McQuail, 2000: 305).

The questions (instruments of measurement) for the doctors and HIV positive mothers are attached in appendices H and I respectively.

3.3 SAMPLE DESIGN

The sampling procedures, or selections of the units of analysis, relevant to this study aim to ensure that the units under observation are as representative of the larger population as possible within the confines of certain study constraints. The sampling procedure for each data collection method is individually outlined below.

3.3.1 Sample selection for the data collection method of content analysis

Time applies as the major constraint to this study. The research question ideally refers to the analysis of nevirapine coverage in all South African newspapers but, as mentioned in Chapter One, such a broad field would render this study "unresearchable" within the allocated time frame:

Due to constraints such as time, costs and personnel, we do not always have access to the actual population (called target population) to which we want to generalise our findings....when this occurs, we have to be realistic and define the accessible population, to which we are able to generalise the findings (Du Plooy, 1997: 50).

The accessible population available for the purposes of a content analysis here is Western Cape daily newspapers presented as a subgroup of the total newspaper population. As such a nonprobability sampling process is used where specific units are chosen vis à vis certain criteria and not every paper in the country has an equal chance of being chosen (Du Plooy, 1997: 54).

The three papers selected for the observation of nevirapine reportage are:

- *Die Burger*

An Afrikaans daily owned by Media24 and first published in 1915. *Die Burger* had a daily readership of 562 000 in 2004 (SAARF AMPS, 2004) and a daily readership of 545 000 in the first six months of 2005 (SAARF AMPS, 2005).

- *The Cape Argus*

An afternoon daily owned by Independent Newspapers. *The Cape Argus* had a daily readership of 407 000 in 2004 (SAARF AMPS, 2004) and 417 000 in the first six months of 2005 (SAARF AMPS, 2005).

- *The Cape Times*

A daily owned by Independent Newspapers and published since 1876. *The Cape Times* had a daily readership of 316 000 in 2004 (SAARF AMPS, 2004) and a daily readership of 252 000 in the first six months of 2005 (SAARF AMPS, 2005).

The three papers were chosen on the basis of meeting certain criteria:

- Newspapers with their main bases in the Western Cape chosen for content analysis allow the researcher accessibility for follow-up in-depth interviews with media practitioners during the second phase of the research

- All three papers are serious broadsheet dailies
- The three papers have a large total readership (1, 285 000) in proportion to the Western Cape population of 4, 524 335 (Western Cape Provincial Government, 2004)
- The readership is relatively race group balanced within the context of Western Cape race group demographics where the majority of the population falls into the Coloured population group:

African/Black population:	1, 207 429
Coloured population:	2, 438 976
Indian/Asian population:	45 028
White population:	832 902
Unspecified	122 148 (Western Cape Provincial Government, 2004).

Die Burger has a 56 percent Coloured readership, a 42 percent White readership and a 2 percent Black readership (Wasserman, 2005); *The Argus* has a 53 percent Coloured readership, a 33 percent White readership, an 11 percent Black readership and a three percent Indian readership; *The Cape Times* has a mainly White and Coloured readership (The Press in South Africa:

www.southafrica.info/ess_info/sa_glance/constitution/news.htm).

Nevirapine reportage in the three papers was observed over a full year from 1 April 2004 to 30 April 2005. This time period was chosen to provide a very recent update on the research completed by Galloway in 2000.

3.3.2 Interviewee sampling

Once again a nonprobability sample was chosen for this second phase of the field research as time constraints prohibited the drawing of a probability sample where all media practitioners have an equal chance of being chosen to participate in the study.

The interviewees, apart from one telephonic interview with a reporter from *Health E*, were selected from Western Cape publications including those under study. As such, the samples were largely accessible for the purpose of in-depth interviewing and ethical care is taken in the final analysis not to generalise the findings to the broader national population of media practitioners (Du Plooy, 1997: 65).

The three editors chosen for the in-depth interviewing process include:

- Chris Whitfield: managing editor of *The Cape Times*
- Estelle Ellis: news editor of *Die Burger*
- A science and health editor who requested to remain anonymous

The four health writers include:

- Willemien Brümmer from *Die Burger*
- Di Caelers from *The Cape Argus*
- Kerry Cullinan from *Health E*
- Johannes de Villiers from *Die Burger*



It is important to note that at the time of writing no health writer was employed by *The Cape Times*.

3.3.3 AIDS experts and the focus group sampling

Once again non-probability samples were selected for the purposes of the third phase of the field research.

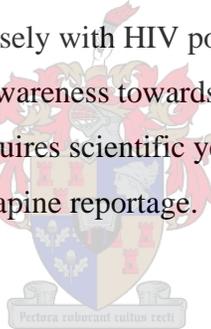
These selected samples are chosen on an exploratory basis, the aim being to test the waters of the public's response to nevirapine press coverage in the Western Cape: "If we want to collect exploratory data to develop a measuring instrument, to pretest a

measuring instrument or to do a pilot study, then a nonprobability sample is appropriate” (Du Plooy, 1997: 55).

The subject of the study concerns the public reception of the media’s portrayal of a drug which directly concerns HIV positive mothers. It is for this reason that the purposive sample of a focus group of HIV positive mothers was chosen: it is these women who can provide the researcher with the information needed: “Previous knowledge of the population, and/or the aim of a study, can result in a researcher using his or her judgement to select the sample, which is then called a *purposive* or *known-group* sample” (Du Plooy, 1997: 62).

This method of sample selection also applies to the doctors interviewed with the aim of having a scientific interpretation of how the public “sees” nevirapine through the eyes of the press. Two doctors who work closely with HIV positive mothers were selected because of their social and cultural awareness towards their patients – a distinct advantage for the researcher who requires scientific yet socially sensitive insight into how the media audience experience nevirapine reportage.

The two doctors selected are:



- Dr Mitchell Besser – director of the NGO The Mothers’ Programme and lecturer in obstetrics at Groote Schuur Hospital
- Dr Inge Paschke – a medical participant in HIV roll-out in Paarl, Malmesbury and Stellenbosch.

The focus group consisted of 11 HIV positive mothers from the Sibanye Economic Empowerment Training Centre in Khayelitsha.

3.4 FIELDWORK PRACTICE

Details of the data collection process for each research method, including access to the units of analysis, procedures used and the dates and settings of data gathering, are discussed below.

3.4.1 In the field with content analysis

The following steps constituted the data collection process for the content analysis phase of the research:

- A primary internet search of newspaper reports on nevirapine facilitated the sourcing of all textual data relevant to this section of the research process. The internet search of reports in the three selected papers saved substantial time in indicating the exact dates of appearance of nevirapine reportage over the chosen time frame
- These indications were then followed up by several visits to the compact storage section of the Stellenbosch University library during the month of July where the relevant articles were swiftly sourced
- The hard copy was researched then and there in the library with data immediately captured onto the coding sheets.

3.4.2 In the field with media practitioners

An important first step in interviewing is the development of a rapport between the interviewer and interviewee (Pitout, 1997: 113). If the interviewee is able to trust the researcher the greater are the chances of a free flow of information. Several steps are taken to ensure that the interviewee feels comfortable with the researcher:

- The purpose of the interview, to gain an insight into the attitude of the journalist towards nevirapine reporting within the context of the role of the media and news values, is made very clear from the beginning

- The informant is told that the interview will respect a time frame of not more than 45 minutes
- Confidentiality of information passed on by the interviewee is assured by the researcher
- Questions are clear (not double-barrelled or complex) so that the interviewee does not flounder and lose confidence
- The interviewee is shown understanding and respect at all times

If these simple guidelines are adhered to “the participant will feel free to reveal his or her innermost beliefs and feelings to the interviewer. This is especially true when those feelings and beliefs are in conflict with the accepted norms of society” (Pitout, 1997: 114).

The in-depth interviews with journalists and editors were carried out in the month of August:

- 
- Appointments were formally set up with the interviewees, explaining the study purpose
 - Interviews were conducted in the offices or work environment of editors and journalists: settings which offer additional information about the participants
 - If permission is granted all interviews are taped; if not, comprehensive notes were made
 - On completion of the interview participants were thanked for their time and contribution to the research.

3.4.3 In the field with the public

The same principles of interviewing technique are applied to the AIDS experts and the members of the focus group as to the media practitioners outlined above.

In order to ensure a level of trust within the focus group between a culturally and socially challenged portion of the public and an unknown interviewer, a co-ordinator was present. This co-ordinator works with and assists these women and so has their trust.

The focus group interviews were conducted in Xhosa, a language unfamiliar to the researcher. In order to prevent valuable information being lost in translation the researcher's questions were:

- firstly professionally translated from English into Xhosa
- thus posed to the focus group in their mother tongue by the group co-ordinator
- interpreted by the group co-ordinator into English
- stored in English on tape by the researcher.

Interviews with doctors and HIV positive mothers were conducted during the month of September.

- 
- Appointments were formally set up with the interviewees, explaining the study purpose
 - Interviews were conducted in the offices of the doctors and during a workshop session in Khayelitsha with the women participating in the focus group study: settings which offer additional information about the participants
 - If permission is granted all interviews are taped; if not, comprehensive notes were made
 - On completion of the interview participants were thanked for their time and contribution to the research.

3.5 DATA CAPTURING AND EDITING

The procedures used in the capturing and editing of data, as well as the measures employed to minimise error, are discussed in this section.

3.5.1 Data capturing process for content analysis

The content analysis coding sheet is so structured as to provide answers for the main research questions.

The capturing and editing of information in the reports on nevirapine follow a simple process whereby each unit of analysis (nevirapine news report) is read and ‘judged’ according to its overall direction as defined in section 3.1.

The coding sheet categories provide the basis for what is essentially a counting system: each statement directly pertaining to nevirapine is scrutinised and placed in a category which sufficiently caters to the statement content.

These categories are negative, positive or neutral in character. The number of subsequent types of statement is then calculated and each news report is given a net score which results in the determination of the overall direction of the report.

Although content analysis is an unobtrusive means of research which allows the researcher “to carry out his observation without fear that the attention will bias the communicator” (Budd, 1967: 2), it is still necessary to employ methods of observation which minimise interpretation error. In the absence of intercoder reliability for this study (due to time and financial constraints), the reliability and validity of this content analysis is all the more dependent on the structure of its coding categories.

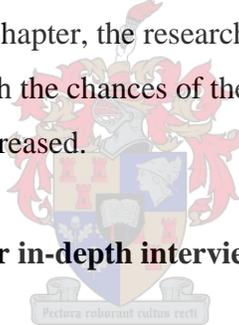
The coding categories are both exhaustive and mutually exclusive. Each statement under analysis within the nevirapine reports should fit into the provided categories. Here “elaborate content categories were developed to minimise coder bias, a major stumbling block in directional analysis” (Budd, 1967: 40). By placing a statement in its proper category, the statement is automatically placed in the correct direction category: a process which minimises the chances of subjective judgement. A miscellaneous category is

included to cover all possibilities, but accounts for a small proportion of the researched material.

The elaborate content category structure aims to guarantee mutual exclusivity whereby every statement fits into only one category (Wigston, 1997: 162). This ensures a clearly demarcated data storage system which provides a solid foundation for reliable analysis. This reliability is further enhanced by the miscellaneous category which offers an alternative storage category and so discourages the researcher from trying to place an item in a category where it does not really belong (which would introduce error into the research findings).

The category structure further minimises error by enhancing the validity of the research. “Validity means that we have measured what we intended to measure” (Wigston, 1997: 164). As mentioned earlier in this chapter, the research questions guided the category choice for the coding sheet. As such the chances of the categories providing answers to the main research questions are increased.

3.5.2 Data capturing process for in-depth interviews with media practitioners



Once the qualitative interviews are conducted and taped they are transcribed verbatim. The transcriptions are then studied and filed: a procedure which involves sorting material into the various categories relevant to the journalism genre as well as any additional categories relevant to the study which may materialise during the interviewing process (Pitout, 1997: 111).

With the interview data thus coded and ‘stored’ in the correct categories, the stage is set for the next phase – the analysis of the collected data.

3.5.3 Data capturing process for in-depth interviews with AIDS specialists and the focus group

As with the interviews with the media practitioners, information yielded by the AIDS experts and members of the focus group is transcribed and stored.

3.6 DATA ANALYSIS

This section describes and rationalises the choice of data analysis procedures for each of the three phases of research. The selected analysis procedures facilitate an explanation of the issues which have been measured and provide a basis from which conclusions can be made about not only *what* is being said but *how* and *why* it is being said and with *what* effect.

The analysis must be a process of discovery about how the key variables interact so that the meta-issues or reasons for what is said about nevirapine and how and why it is said come to light.

3.6.1 Analysis of data collected through content analysis

The data is analysed primarily from a conceptual stance which is quantitative in nature and:

can be thought of as establishing the existence and frequency of [negative or positive]concepts in a text.... In conceptual analysis, the researcher simply wants to examine presence with respect to his/her research question, i.e. whether there is a stronger presence of positive or negative words used with respect to a specific argument or respective arguments (Palmquist, undated: 2).

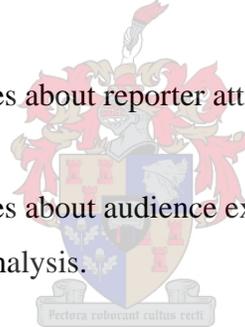
In this study each nevirapine report is given a net score calculated from the coding sheet which is constructed around negative and positive categories. The category system in the coding sheet thus provides data (the net scores) for the next step in the analysis which looks beyond this 'counting' stage and is qualitative in nature by examining how

environmental factors such as media practitioners and the community relate: “The category system – direction and content – had to provide data for correlation analysis with community variables” (Budd, 1967: 40).

The qualitative analysis in this context is relational which “builds on conceptual analysis by examining the relationships among concepts in a text” (Palmquist, undated: 1).

Qualitative analysis judges ‘how’ nevirapine is reported and ‘why’ nevirapine is reported in certain ways. Here the researcher:

- analyses the quality of reporting (“message handling”) on nevirapine from scientific, educational and culturally sensitive viewpoints: “Krippendorf (1980) uses the term ‘performance analysis’ to refer to research designed to find answers about the *quality* of the media as judged by certain criteria” (McQuail, 2000: 305)
- attempts to make inferences about reporter attitude to nevirapine based on the texts under analysis
- attempts to make inferences about audience experience of nevirapine reportage based on the texts under analysis.



The analysis procedure is thus multiple correlation analysis “which involves analysis of the relationship between one dependent variable...and two or more independent (predictor) variables” (Budd, 1967: 77). The dependent variable is the experience (positive or negative) of the media audience which depends on the attitude of reporters towards nevirapine and the quality of reporting on the drug. In other words, through an examination of reporter attitude and reporting quality the researcher can “predict” the reader’s experience of nevirapine.

3.6.2 Analysis of data collected through interviews with media practitioners

The data collected through in-depth interviews with media practitioners is analysed from a predominantly qualitative perspective to attempt an understanding of their attitude to nevirapine.

This data is used in correlation with the quantitative directional data collected in phase one. By relating data collected through interviews to the frequency of negative or positive text direction 'counted' in phase one, a "thick" description is revealed and accounts for the direction of nevirapine reporting: "In a thick description, the voices, feelings, actions and meanings of interacting individuals are heard" (Mouton quoting Denzin, 2001: 188). Qualitative analysis requires an account:

of links and relationships between elements in the text, and also to take note of what is missing or taken for granted. We need to identify and understand the particular discourse in which a text is encoded. In general we need to be aware of the conventions and codes of any genre that we study, since these indicate at a higher level what is going on in the text (McQuail, 2000: 325 quoting Jensen and Jankowski).

The researcher's understanding and assumptions about the latent meanings in the text (including reporter and editor attitude to nevirapine) gleaned from the content analysis gain reliability or are enhanced in the second phase of the study through the interviewing process. The analysis of the data in this phase offers an explanation of nevirapine reportage by considering those themes central to the genre of journalism within in the context of science journalism in a developing country like South Africa:

- the perceived role of the media
- news values
- sources
- reporter ability to convey complicated scientific concepts to the public in a simple and clear manner

- journalists' working knowledge of nevirapine from a scientific and treatment perspective
- gender awareness/sensitivity within the patriarchal society.

Rubin and Rubin offer an analytical process, based on the grounded theory approach, conducive to this section of the study:

Data analysis begins while the interview is still underway. This preliminary analysis tells you how to redesign your questions to focus in on central themes as you continue interviewing. After the interviewing is complete, you begin a more detailed and fine-grained analysis of what your conversational partners told you. In this formal analysis, you discover additional themes and concepts and build toward an overall explanation. To begin the final data analysis, put into one category all the material from all your interviews that speaks to one theme or concept. Compare the material within the categories to look for variations and nuances in meanings. Compare across the categories to discover connections between themes. The goal is to integrate the themes and concepts into a theory that offers an accurate, detailed, yet subtle interpretation of your research arena. The analysis is complete when you feel that you can share with others what your interpretation means for policymaking, for theory, and for understanding the social and political world (Rubin & Rubin, 1995: 226-227).

3.6.3 Analysis of data collected through interviews with doctors and focus group

The researcher has established that “content on its own cannot be taken as evidence of effect” (McQuail, 2000: 305). The interviews in the final stage of the research process are conducted to further test the researcher's study expectations and to validate the findings from the first two stages of the field research.

The interviews are qualitative in nature and explore both the public's perception of nevirapine and the predominant reasons for this perception.

The respective interviews with doctors and HIV positive women provide opinion at two different levels: the science take and the public take. The results are then analysed in relation to each other to deepen the validity of the findings.

3.7 SHORTCOMINGS AND SOURCES OF ERROR

It is possible that the quality of the data collected in any research process may be affected by shortcomings inherent to data collection methods. It is necessary to highlight these possible sources of error and demonstrate how attempts have been made to minimise their negative impact.

3.7.1 Disadvantages of content analysis

Within the context of this study the main source of error can be linked to the nonprobability sampling method used as described in section 3.3.1. A nonprobability sample prevents the determination of the amount of sampling error present (Du Plooy, 1997: 54).

In order to make allowances for this lack of determination and 'save' the validity of the research, the researcher carefully based her choice of newspapers on criteria which gave as fair a representation as possible of the most read papers across Western Cape population groups: "A small, carefully chosen sample of the relevant content will give just as valid results as the analysis of a great deal more" (Berelson quoted in Budd, 1967: 20).

It is imperative to point out, however, that although the data collected from these samples is useful in describing the situation in the Western Cape, it cannot be used to generalise about the situation in the rest of South Africa. When using a nonprobability sample "great

caution must be exercised in generalising from the findings of studies that use this sampling method to all other units comprising the population from which the samples are selected” (Budd, 1967: 24).

Further disadvantages of content analysis include:

- Increased error when relational analysis is used to attain a higher level of interpretation
- A disregard of the context that produced the text
- Too liberal attempts to draw meaningful inferences about the relationships and impacts implied in a study (Palmquist, undated: 3).

It is hoped that phases two and three of this research process (in-depth interviews with media practitioners and a focus group study with members of the public) will increase the validity of the content analysis findings by confirming the inferences drawn following the qualitative analysis of the conceptual data. In-depth interviews aid in the interpretation of the content by providing a “thick” description of the analysis:

A thick description does more than record what a person is doing. It goes beyond mere fact and surface appearances. It presents detail, context, emotion and the webs of social relationships that join persons to one another (Denzin quoted in Mouton, 2001: 103).

3.7.2 Disadvantages of interviews

Although in-depth interviews can yield a wealth of information if the rapport between the interviewer and interviewee is good, they are not without their disadvantages.

As discussed above in section 3.3.2, “because an in-depth interview is typically done with a nonrandom sample, generalisability is often a problem” (Pitout, 1997: 114). It is therefore important to take care to relate the final findings of the interview research to

Western Cape media practitioners and not to extend the findings to the rest of South Africa.

Further disadvantages of in-depth interviews include:

- Uncooperative participants
- Researcher's loaded questions or tone of voice which elicit a biased response from the interviewee
- Difficulty in coding and thus analysing transcribed data (Pitout, 1997: 114).

These disadvantages can, to a large degree, be overcome by:

- The interviewer's good listening skills and his/her ability to nurture a relationship of trust in a short space of time
- The skilful framing of questions on the part of the interviewer: no leading questions which communicate interviewer bias; no double-barrelled questions which fluster the interviewee
- The construction of exhaustive and mutually exclusive coding categories for the filing of volumes of data collected through the interviewing process. If the coding categories are exhaustive and mutually exclusive, themes and concepts gleaned from the interviews are more easily categorised for analysis.

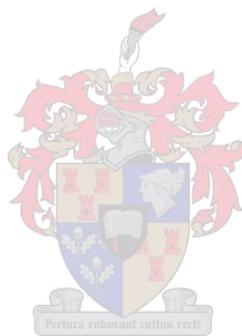
3.7.3 Disadvantage of interviews with AIDS experts and members of the focus group

The same principles of disadvantage and attempts to overcome these disadvantages basically apply to the interviews in this section as to those outlined above for the media practitioners. Two exceptions are made:

- in the focus group study where language poses a problem in that the researcher is not fluent in Xhosa. As mentioned above in section 3.4.3, however, attempts in

the form of satisfactory translation and interpretation were made to overcome the problem.

- The researcher did not work from exhaustive and mutually exclusive coding categories for interviews with AIDS specialists and members of the public – a “general impression” analysis was adopted instead.



CHAPTERS 4 FF.: RESULTS: PRESENTATION AND DISCUSSIONS

The following three chapters document and discuss the results of the three stages of the fieldwork research, namely:

- The content analysis of the chosen publications which describes and evaluates the media content of nevirapine reportage
- The in-depth interviews with media practitioners which offer a causal explanation for the media content of nevirapine reportage
- The in-depth interviews with medical specialists and the focus group study which, together, explore and evaluate the public's perception of nevirapine via the press.

CHAPTER 4: RESULTS OF THE CONTENT ANALYSIS

4.1 Presentation of the content analysis results in graph and table form

The content analysis involved a largely relational analytical process preceded by an initial structural approach to the 83 press reports on nevirapine.

The graphs and tables below, therefore, record both:

- a quantitative or structural count of articles as a measure of coverage on nevirapine and the positive/negative or neutral direction within that coverage
- the substantive or qualitative relationships between the text concepts. Here the recorded results begin to indicate, as the quality of science reporting on nevirapine begins to unfold, why the direction is largely positive or negative.

4.1.1 The existence and frequency of nevirapine reportage and content direction therein

Figure 1: Press coverage of nevirapine per selected publication from 01/04/2002 to 30/04/2005

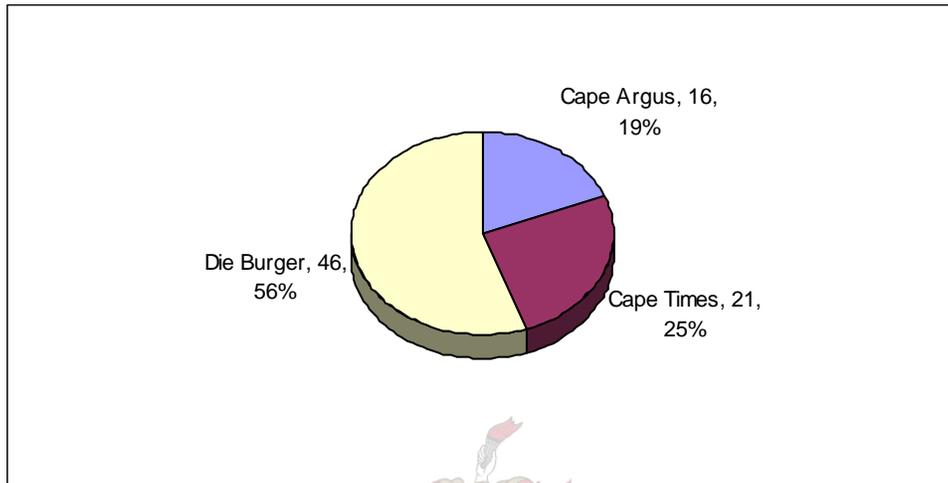
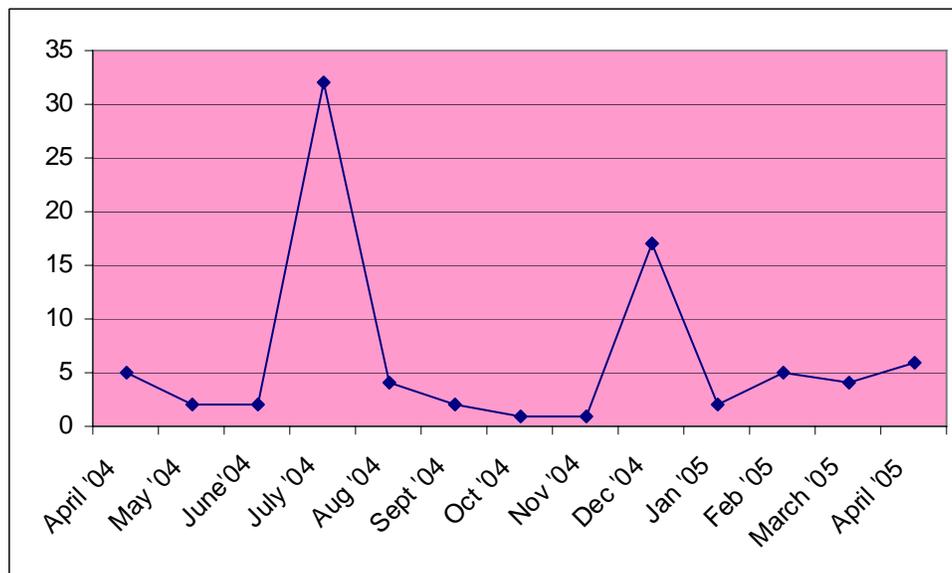


Figure 2: Overall peak pattern for nevirapine reportage between 01/04/2004 and 30/04/2005



Figures 3 ff.: The direction of nevirapine reportage between 01/04/2004 and 30/04/2005

Figure 3a: Overall

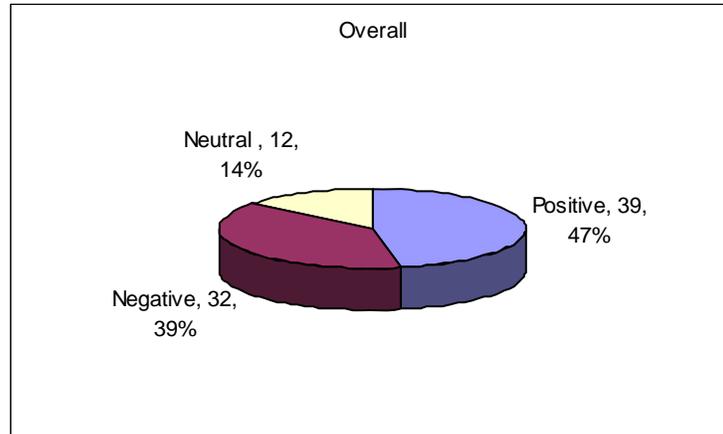


Figure 3b: *The Cape Argus*

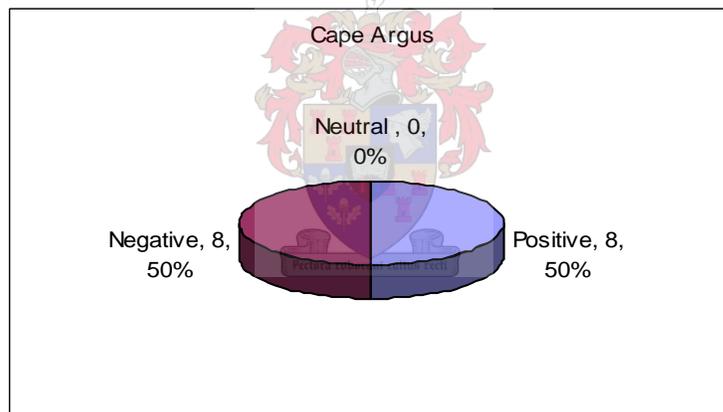


Figure 3c: *The Cape Times*

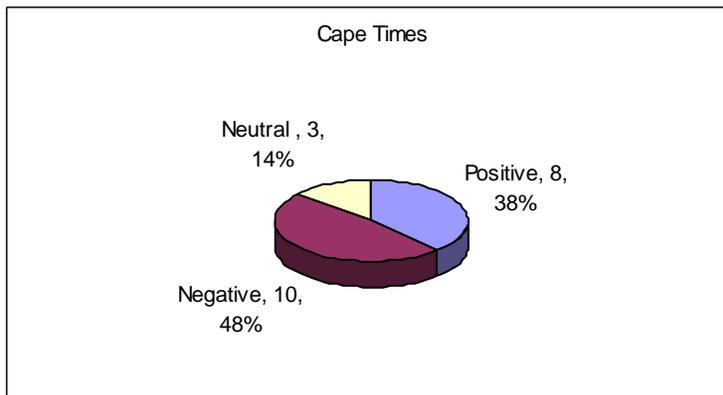
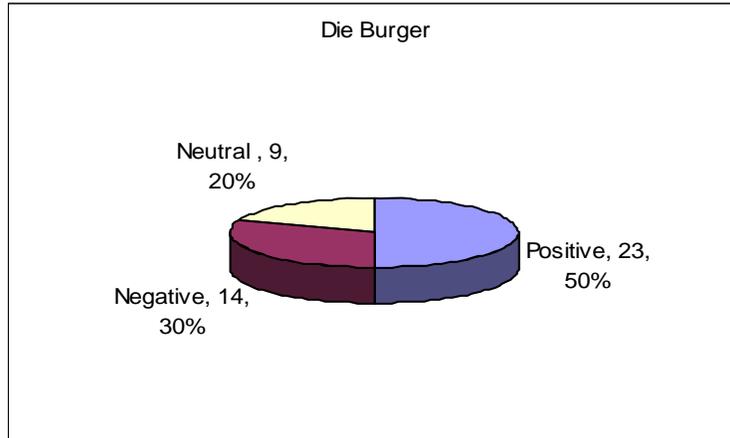


Figure 3d: *Die Burger*



4.1.2 The relationships between the text concepts

Figures 4 ff.: Sources used in nevirapine reportage from 01/04/2004 to 30/04/2005

Figure 4a: Overall

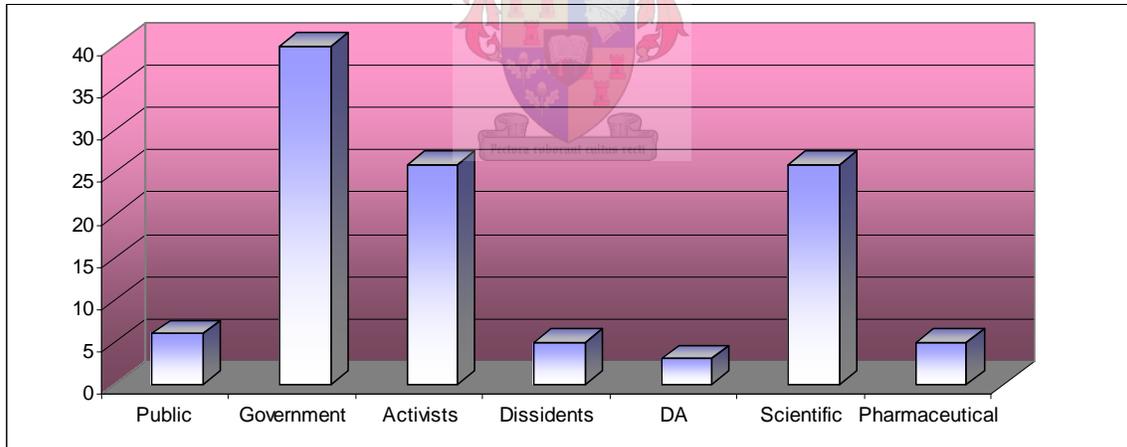


Figure 4b: *The Cape Argus*

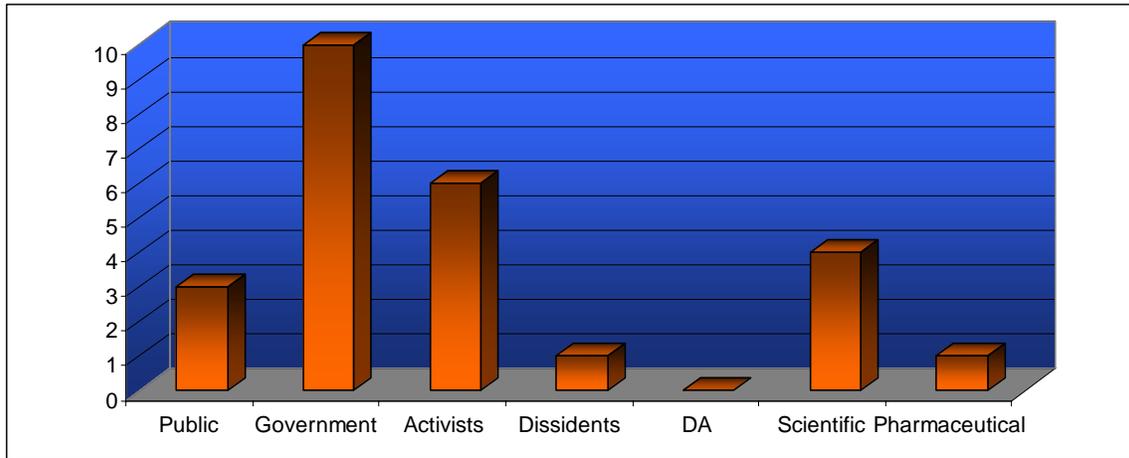


Figure 4c: *The Cape Times*

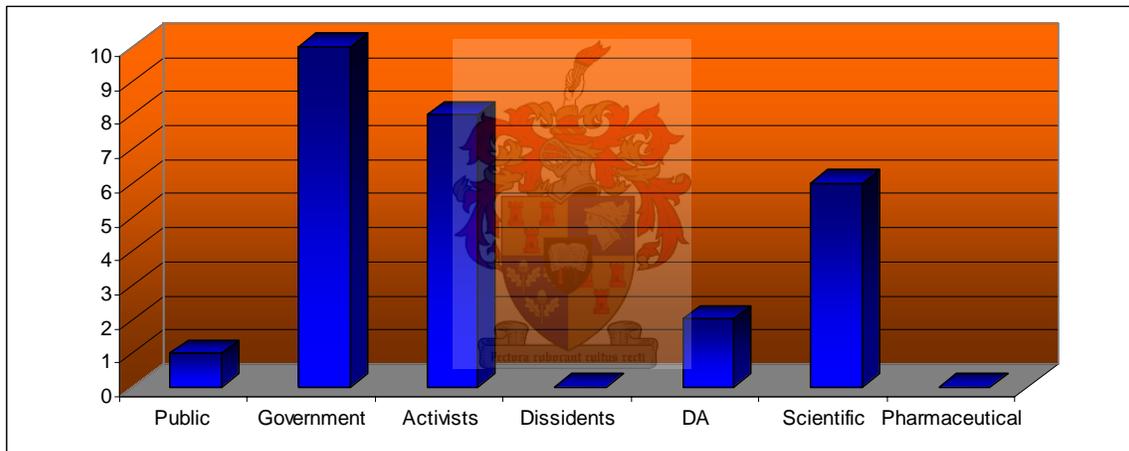


Figure 4d: *Die Burger*

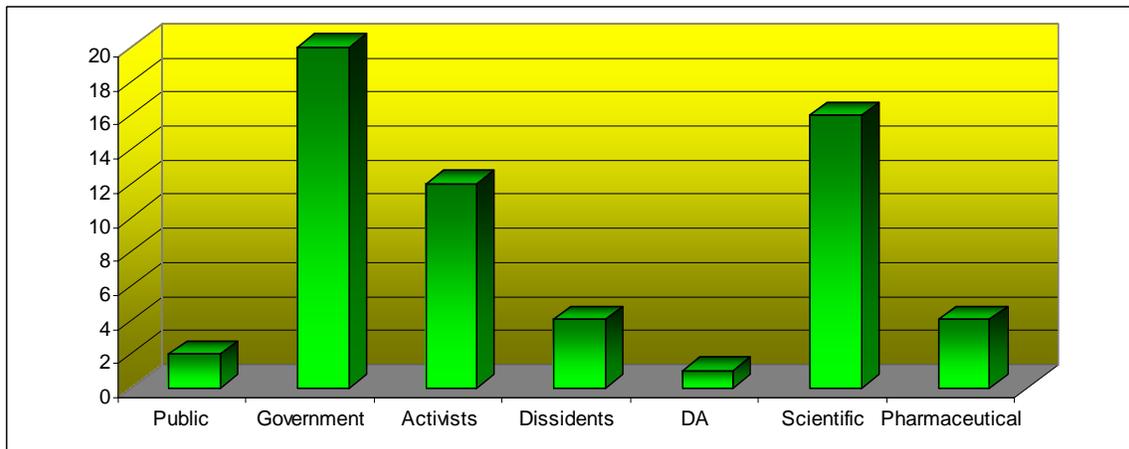


Figure 5: Correlation between sources used and content direction in nevirapine reportage between 01/04/2004 and 30/04/2005

OVERALL					
	Public	Government	Activists	Aids Dissidents	Scientific
Total Sources	4	40	24	5	26
+	3	16	6	1	20
-	1	22	16	4	2
0	0	2	1	0	4
CAPE ARGUS					
Total Sources	3	10	6	1	4
+	2	4	2	0	4
-	1	6	4	1	0
0	0	0	0	0	0
CAPE TIMES					
Total Sources	1	10	6	0	6
+	1	2	0	0	4
-	0	8	6	0	1
0	0	0	0	0	1
DIE BURGER					
Total Sources	0	20	12	4	16
+	0	10	4	1	12
-	0	8	7	3	1
0	0	2	1	0	3

Figure 6: Number of single sources used overall and per newspaper with direction denoted
(Please refer to Appendix Q where table, due to incompatible space layout, is stored)

Figures 7 ff.: Agendas set in nevirapine reportage between 01/04/2004 and 30/04/2005

Figure 7a: Overall

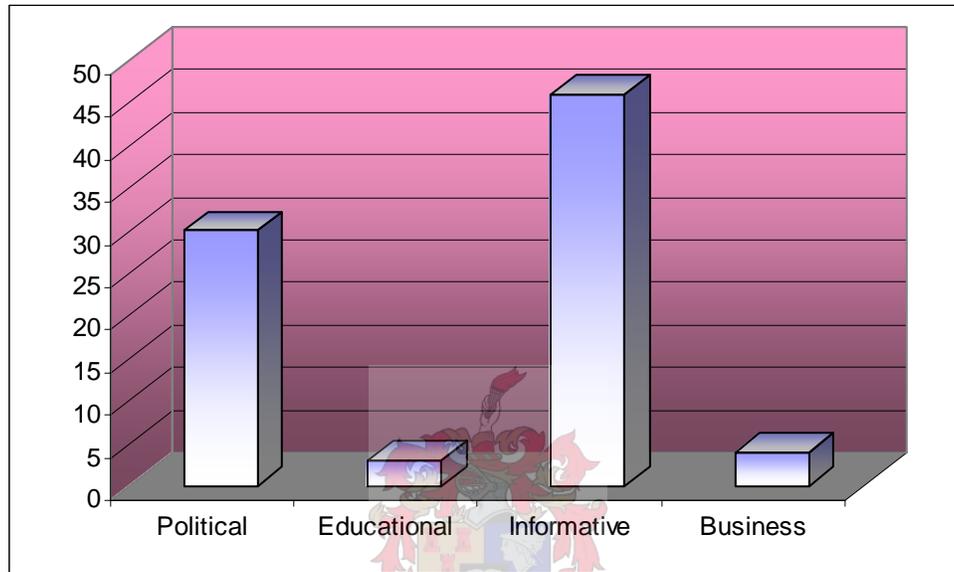


Figure 7b: *The Cape Argus*

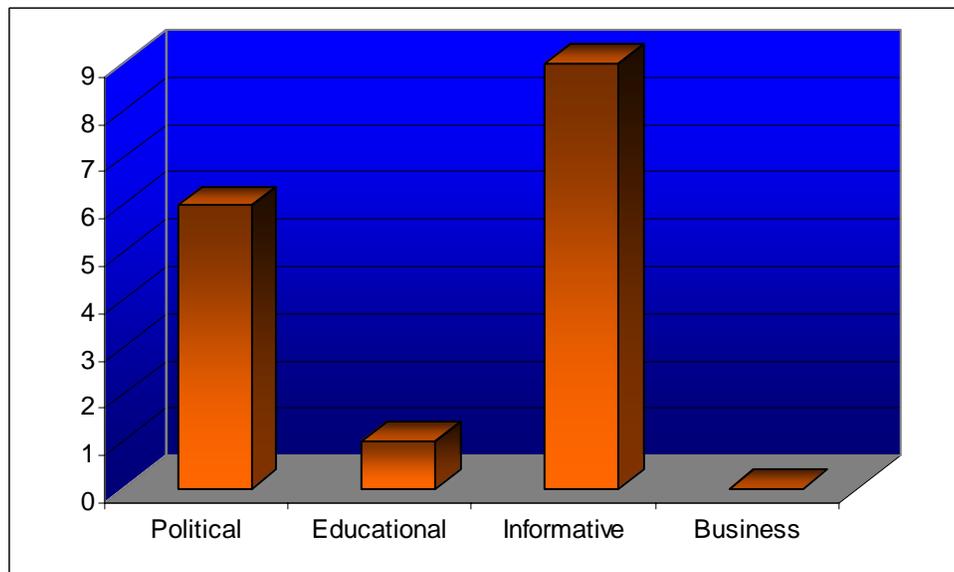


Figure 7c: *The Cape Times*

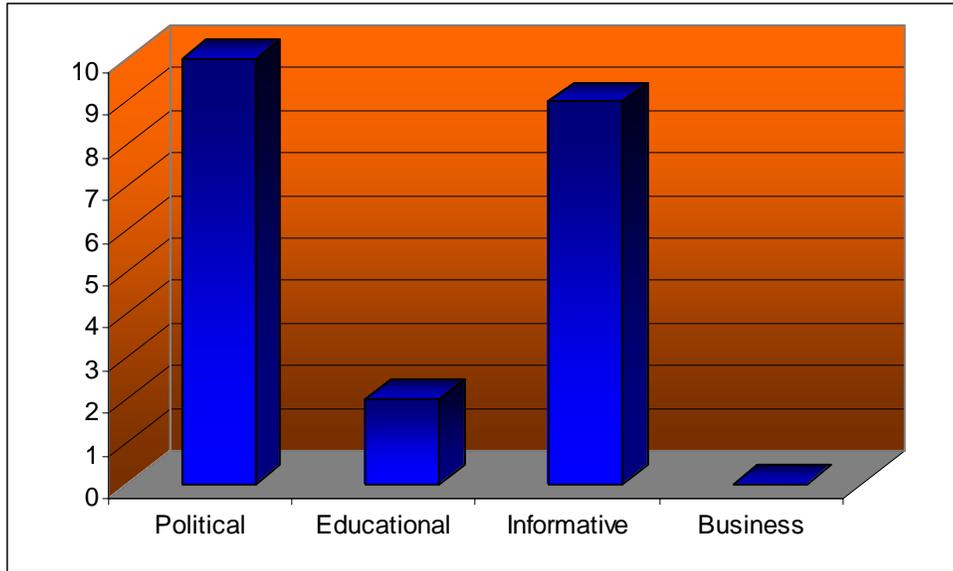
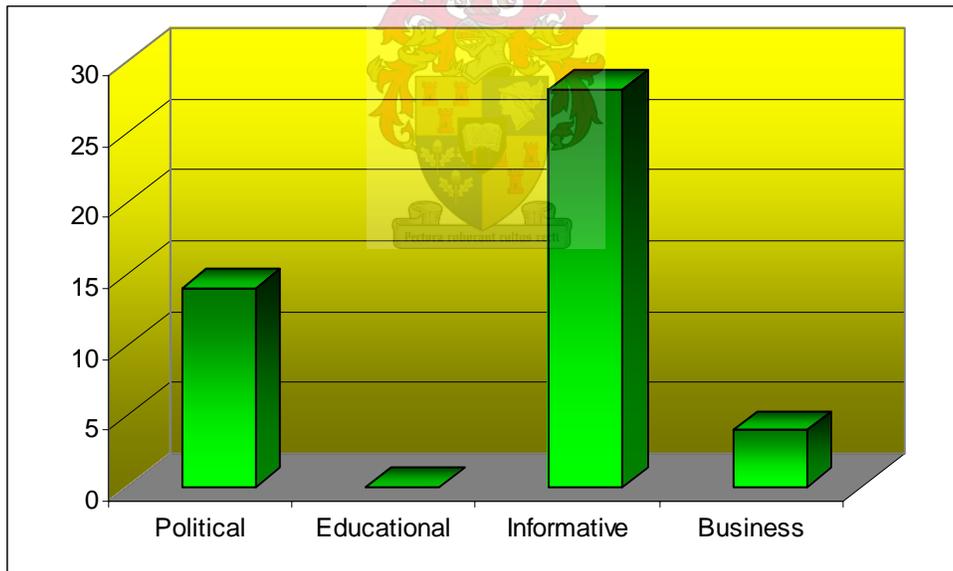


Figure 7d: *Die Burger*



4.2 Discussion of results by expectations and themes

Here the main trends and patterns in the data are discussed with reference to the original research questions and study expectations.

4.2.1 Discussion of the frequency of nevirapine reportage and content direction therein

A major expectation of this study was that the South African media was largely unaware of the enormous responsibility it carries in the portrayal of nevirapine. As such, an exploration of the coverage of the drug, from both a frequency and negative content perspective, yielded interesting results.

These first results are quantitative in nature and are reflected in Figures 1 to 4ff.

Figure 1 records the existence of nevirapine reports between April 1, 2004 and April 30, 2005 in the three selected daily publications: *The Cape Argus*, *The Cape Times* and *Die Burger*. Overall there were 83 reports over this time period. *Die Burger*, with a contribution of 46 articles, was responsible for more than half of these reports, *The Cape Times* printed 21 articles and *The Cape Argus* 16.

Figure 2 shows that nevirapine reportage peaked at two distinct periods over the course of the year. All three publications reported more on the drug at high points of controversy during nevirapine's recent history. In July 2004 coverage increased dramatically during the International AIDS Conference in Bangkok where the questioned reliability of single-dose nevirapine once again claimed centre stage. In December 2004 reporting also increased during renewed controversy over single-dose nevirapine sparked by the Associated Press's dissemination of misinformation over the reliability of the Ugandan HIVNET 012 clinical trial. Apart from these periods, nevirapine press coverage was erratic and thin at best.

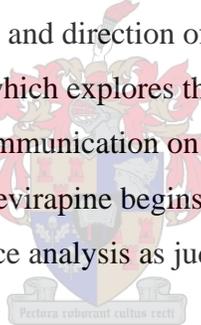
In its exploration of the content direction of nevirapine press coverage, the study revealed that in the overall coverage from the three publications, the percentage direction was marginally more positive than negative when judged over the three direction categories of positive, negative or neutral. Figure 3a records, however, that although there is a slightly higher number of positive (39) reports than negative (32), this is not enough to push the

overall positive nevirapine reportage into the 50 percent or above category: this is due to the “dilution” effect of the neutral number of reports (12). The overall positive direction of nevirapine reportage for the specified time period therefore rests at 47 percent which although relatively low is, at least, higher than the negative direction percentage of 39 percent, albeit by a slim margin.

Figures 3b to 3d show that only *Die Burger* had a more positive than negative direction content in its nevirapine reportage. *The Cape Times* had a more negative than positive content direction and *The Cape Argus* had equal negative and positive content direction.

4.2.2 Discussion of the quality of nevirapine reportage

Here the discussion of the results from the content analysis shifts from a structural, “counting” approach of the existence and direction of nevirapine reportage to a more substantive or qualitative approach which explores the reasons for the content direction status and the standard of science communication on the drug. The quality of journalistic message handling of issues around nevirapine begins to unfold as the recorded results offer an opportunity for a performance analysis as judged by various criteria.



These criteria refer back to several of the study’s original research questions and include:

- Sources used
- Correct/incorrect scientific information on nevirapine and a journalistic in-depth knowledge (or lack of) of the clinical features and benefits of nevirapine
- Agendas set

4.2.2i The journalistic use of sources plays a significant role in determining the content and readership experience of reporting on nevirapine.

Figure 4a reveals that government sources were relied on extensively by journalists in their portrayal of nevirapine in the selected time frame. A total of 40 government sources

were used overall; 26 scientific sources; 24 activist (mainly TAC) sources; five AIDS dissident sources and a mere total of four public voices. All three publications resorted to government sources more than any other source. *Die Burger* used more scientific (16), than activist sources (12), *The Cape Times* equal science and activist sources (six) and *The Cape Argus* more activist (six) than scientific (four). *The Cape Argus* quoted three members of the public, *The Cape Times* one and *Die Burger* none. Of all these public sources only one was a woman (*The Cape Argus*, 1 December, 2004: 22). *Die Burger* made the most use of AIDS dissidents (four), *The Cape Argus* once and *The Cape Times* not at all.

Figure 5 shows the overall correlation between the use of government sources and the subsequent largely negative content direction. There is also a strong negative content direction outcome when activists and AIDS dissidents are relied on as sources in nevirapine reportage. When public and scientific sources are used, however, it can be seen that there is a high positive content direction in the nevirapine reports.

Figure 5 further demonstrates that this overall correlation between source type and content direction is reflected in each publication individually apart from *Die Burger* where slightly more reports using government sources have a positive content direction.

Figures 4 to 5 record results vis à vis multi-sourcing as well as single-sourcing. Figure 6, on the other hand, records the number of single sources alone and the subsequent content direction. These results highlight the “dangerous” sources within the context of nevirapine reportage. “Dangerous” sources, within the context of this study, may be defined as government, activists and AIDS dissidents. When these sources are used alone, without the balancing effect of other less biased or scientific sources, the content direction is largely negative.

This is vividly demonstrated in the case of *Die Burger* where Figure 5 shows the general use of “dangerous” sources such as government (including both single government sourced and compounded government sourced reports) as resulting in slightly more

positive content direction. Figure 6, however, demonstrates clearly that a government source when used alone by all three publications, including *Die Burger*, tends to result in a largely negative content direction: four of *Die Burger's* eight government single sourced reports have a negative content direction, three a neutral direction and one a positive direction.

Figure 6 further indicates that single-sourced reports which have, on the other hand, used “safe” science and public sources within the context of nevirapine reportage have a strong positive content direction.

4.2.2ii It is important, at this point, to further dissect the quality of science reporting on nevirapine by looking beneath the use of source to the resultant standard of the communication of scientific, clinical and treatment issues surrounding the drug.

Selected examples from the 83 reports of the message handling of these issues offer a “bird’s eye” record which highlights the main areas of success and failure in the South African media management of nevirapine.

These results, recorded here as selected examples, are presented as they have been categorised in the content analysis coding sheet. Once again these results are discussed with reference to the research questions which themselves defined the coding sheet categories.

The quality of the communication of scientific facts and treatment information surrounding nevirapine is central to this study. The recorded examples below indicate that it is on issues of treatment distinction, resistance, toxicity and statistics that media practitioners are most challenged in their presentation of accurate information.

In January this year *The Cape Argus* reported:

The US Food and Drug Administration (FDA) warned on Wednesday that doctors should weigh benefits and risks before prescribing Viramune [nevirapine], which was linked with some deaths, including in pregnant women (*The Cape Argus*; 21 January, 2005: 5).

This statement demonstrates a lack of responsible health reporting. The report is relating to the 1999 HIVNET 012 trial on sdNVP, yet the reporter has failed to distinguish between sdNVP and nevirapine used as part of a combination therapy. The use of sdNVP has never been linked to death or liver failure, whereas nevirapine combination therapy has. The reporter's ignorance of this very important fact has allowed for confusion, on the reporter's behalf, between the two Associated Press articles in December last year where one reported on sdNVP and the other reported on the death of an American woman due to liver failure through the use of nevirapine combination therapy.

The same mistake is seen in another *Argus* report in December last year, following the AP reports:



It emerged yesterday that American health officials suppressed warnings two years ago about some of nevirapine's serious side-effects. Top US health officials under-reported severe reactions, including death, during a Ugandan study in 2002 (*The Cape Argus*; 15 December, 2004).

And again in *The Cape Times*:

The department was responding yesterday to disclosures that US National Institutes of Health officials had warned that Ugandan research on nevirapine was flawed and that severe and possibly lethal reactions to the drug may have been under-reported (*The Cape Times*; 16 December, 2004).

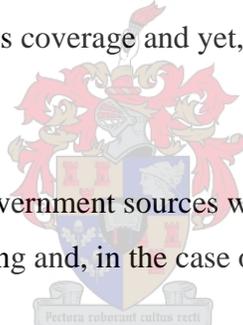
And in *Die Burger*:

Vrae oor die nuwe-effekte van nevirapien het ontstaan toe in 'n studie wat in Uganda gedoen is, bevind is dat nevirapien in sommige gevalle tot die dood kan lei (*Die Burger*; 20 Desember, 2004: 2).

Dr. Rachel Cohen, van Doctors Without Borders, het aan *The New York Times* gesê dit is jare al bekend dat eenmalige gebruik [van nevirapien] nuwe-effekte soos 'n uitslag op die vel en lewersaking kan veroorsaak (*Die Burger*; 22 Desember, 2004). [This last example appears as a quote from a science source but is incorrect: either the reporter has misquoted the medical expert or failed to pick up the error from the medical source].

It is important to note that these examples all come from reports published during one of the peak periods of nevirapine press coverage and yet, distressingly, they carry incorrect scientific messages.

It is also interesting to note that government sources were used in each of the above reports both as part of multi sourcing and, in the case of *The Cape Times* report, as a single source.



Nevirapine resistance is a complicated issue which as yet still requires extensive scientific research. It is useful, at this point, to re-instate the complexity surrounding the question of the effectiveness of future AIDS therapy after the use of sdNVP. Senior AIDS specialist, Professor Helmuth Reuter of the Department of Immunology and Infectious diseases at Tygerberg Hospital, states:

The effect of using nevirapine as a single agent in the prevention of MTCT is certainly associated with the risk of resistance. It is, however, not known whether this is of clinical significance or not. A triple therapy ARV treatment regimen would still be effective in suppressing viral

replication, even when/if it contains nevirapine or efavirenz. However, the risk for further resistance may be increased (Reuter, 2005).

This reliable scientific opinion can be used to highlight journalistic oversimplification of the resistance issue:

The controversy of sdNVP ... has simmered for years, specifically around the threat of women becoming resistant to the drug. This could affect their own treatment later in their illness (*The Cape Argus*; 12 January, 2005: 12).

Die MI-virus kan so weerstandig raak dat bestaande kombinasies dit nie meer stuit nie (*Die Burger*; 29 June, 2004).

As well as oversimplifying HIV resistance to nevirapine, reporters sometimes confuse the two very different issues of resistance and toxicity:

Die MBR het navorsing bekend gemaak wat toon 'n enkeldosis nevirapien kan teenreaksies hê en dus skadelik wees vir die gebruiker (*Die Burger*; 22 July, 2004).

Lastly, in the communication of correct scientific details on nevirapine, statistics can be misrepresented with alarming results. The following report, in its brief entirety, holds the potential to create unnecessary concern for patients on the Government's Prevention of MTCT Programme as well as any other mother considering the use of nevirapine to prevent MTCT:

Die DA het gister gevra vir 'n dringende hersiening van die regering se program om ma-na-kind-oordrag van MIV/vigs te keer nadat dit aan die lig gekom het 43% van alle babas wat tans deel van die program uitmaak, toets steeds MIV-positief.

Van die 1 941 wat tussen April en September 2003 by geboorte vir MIV getoets is, het 832 in 2004 MIV-positief getoets – vier keer meer as die internasionale standaard.

‘Dit is ook ver meer as die 25 %-MIV-oordrag by geboorte wanneer nivrapien nie gebruik word nie,’ het mnr. Ryan Coetzee, adjunkwoordvoerder van gesondheid vir die DA, gister in ‘n verklaring gesê (*Die Burger*; 23 March, 2005).

The DA’s demand for an inquiry into the Government’s MTCT programme was based on incomplete statistical results: a fact put right by a subsequent report in *Die Burger* the very next day (see appendix X). There is the strong possibility, however, that some seeds of doubt, somewhere, would have already been sown.

It is important, once again, to note that the source of the erroneous report was a political source - the Democratic Alliance, the official opposition to the ANC.

The success of South African newspaper reporting on nevirapine depends very much on whether or not scientific sources are used. The following examples indicate that the use of reliable sources results in a positive portrayal of nevirapine and a high positive content direction score:

Abdullah [Dr Fareed Abdullah, head of AIDS programmes in the Western Cape] meen dat ‘n enkelosis nevirapien die oordrag van MIV van ma na kind aansienlik kan verminder (*Die Burger*, 24 July 2004: 4);

and, in the report entitled “Nevirapien op 28 weke kan nou nóg babas red” (*Die Burger*, 16 July 2004), three science sources and only one government source are used resulting in a very high positive score of + 15.

4.2.2iii The use of source also plays an integral role in determining not only the direction of the media content around nevirapine but also the set agenda. Figures 7 ff.

indicate the promoted agendas by the three dailies during their portrayal of nevirapine over the selected time period.

Before embarking on a discussion of these recorded results, it is necessary to define the depicted agenda categories as experienced by the researcher:

- “Political” refers to those agendas promoting organisation interests to the exclusion of the promotion of accurate treatment, clinical and scientific facts of nevirapine. These include organisations such as the ANC, the DA, the activist organisation TAC and AIDS dissident organisations or individuals
- “Educational” refers to those agendas which speak directly to the public on clinical, treatment and scientific issues surrounding nevirapine which empower the public in their knowledge of the drug to the extent that they are able to make informed decisions with regard to its use
- “Informative” refers to those agendas which inform the public on happenings regarding nevirapine such as policy decisions, authoritative attitude (including government and medical experts), reviews and conferences on and around nevirapine. These are not educational agendas
- “Business” refers to those agendas which discuss the manufacture, marketing and sales of nevirapine.

Figure 7a shows that the main agendas set when reporting on nevirapine are, in order of descent, informative, political, business and educational.

Figures 7b to 7d reveal that the main agenda set by all publications is informative with the exception of the *Cape Times* which sets a mainly political agenda.

These selected dailies are not business newspapers and so the business agenda is low. None of the papers, however, appear to place much value on an educational agenda with regard to health reporting around nevirapine: *Die Burger* gives no space at all to an

educational angle and *The Cape Argus* and *The Cape Times* have a very low educational perspective in proportion to their political and informative agendas.

Having established the agenda status of the selected dailies, it is now imperative to once again refer to the question of sources in relation to these agendas and to the quality of science and health information communicated to the public through these channels.

Once again selected examples from the 83 reports present an overall idea of how sources and agenda may affect the public experience of nevirapine reportage.

Within the context of the high political agenda set by the selected newspapers, it is necessary to extract and evaluate reported statements from the political organisations mentioned above.

Section 4.2.2i demonstrates that the newspapers under study rely largely on government sources when reporting on nevirapine issues. As a result a high number of political agendas are set. In addition to this high political agenda content, there is a high level of informative reporting which covers government attitude to nevirapine. It is, unquestionably, a newspaper's duty to inform, but within the context of this study it is necessary to consider seriously what information and which attitudes are being dispelled through the channels of political and informative agendas.

The voice of the ANC rings out loud and clear through the media in response to the December 2004 controversy over the Ugandan HIV NET 012 clinical trial:

The article [from the ANC] included a report on a Ugandan study on the effects of Nevirapine, saying Africans were being used as 'guinea pigs' (*The Cape Times*, 21 December, 2004: 6).

Similar laments are reported during the 2004 International AIDS Conference in Bangkok:

The minister drew attention to recent research findings which suggest that a dose of nevirapine given to a mother and child at the time of delivery produced resistance to the medication and blamed civil society organisations for forcing this regimen on the health department (*The Cape Times*, 12 July, 2004: front page).

Statements such as these, which use words such as “guinea pigs” and “forced regimens”, may be considered as erroneously portraying the South African public as victims of an evil drug and can only serve to further confuse and disempower a largely under-informed and insecure people.

Public confusion about nevirapine is further exacerbated by reports of the government’s endless and on-going bickering with TAC:

Die TAC is gister in a ‘n artikel in die weeklikse internetpublikasie van die ANC, ANC Today, uitgekryt vir ‘n organisasie wat voorgee om Afrikane se belange op die hart te dra, maar terselfdertyd ‘nie skroom om die lewens van Afrikane ondergeskik te stel nie’. Die artikel ... sê dit was reeds jare gelede duidelik dat nevirapien skadelik is vir mense, maar die TAC het steeds voortgegaan om die regering ‘te dwing’ om dit landwyd beskikbaar te stel (*Die Burger*, 18 Desember, 2004: 2).

Government authoritative attacks such as these on activist organisations sensationalise the risks of nevirapine (“nevirapien skadelik is vir mense”) turning the drug into a mere tool for political gain. The report ends with a reference to Jesse Jackson:

In die artikel word eerw. Jesse Jackson, Amerikaanse politikus, ook aangehaal waar hy vra vir die onttrekking van enige medisyne wat die VSA aan Afrika gee, omdat die navorsing in Amerika nie van goeie gehalte is nie (*Die Burger*, 18 Desember, 2004: 2).

It is the media's unbalanced portrayal of comments such as these that have the potential to create a real dilemma for users and potential users of the drug. The article is available in appendix X and serves as an example of dangerous single-sourcing and subsequent unbalanced reporting on nevirapine with a potentially disastrous effect on the readership. It would appear that the journalist does not "see" the reader and is insensitive to the social and cultural challenges of the public in general.

As well as in the main body of the text, government's negative attitude to nevirapine is often reflected in headlines when informative or political agendas rule:

US report supports doubts on nevirapine (*The Cape Argus*, 15 December, 2004).

Government welcomes US nevirapine doubts (*The Cape Times*, 16 December, 2004).

Thus, at a glance, the public may immediately experience a negative response to the drug.

A public sensation of hopelessness and victimisation may, ironically, be further instilled by reports which extensively utilise the AIDS activist group TAC. When journalists rely heavily on TAC as information sources for nevirapine issues, a very strong political agenda is set and the content direction, as demonstrated in by Figure 5, is largely negative.

Although TAC is well-intentioned in their efforts to make AIDS drugs easily accessible to those who need them, the HIV-positive public is invariably portrayed as victims of an unjust Health Department and used as a political pawn in TAC's battles against the government.

This is evident in headlines such as this:

SA laughing stock after AIDS summit – Achmat (*The Cape Times*; 28 July, 2004)

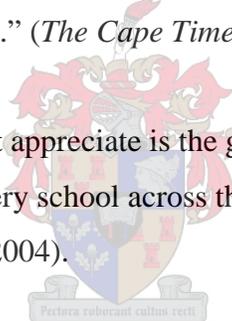
Departement mislei SA oor nevirapien (*Die Burger*, 17 December, 2004: 18)

Manto verwar SA net, sê Achmat by kongres (*Die Burger*, 15 July, 2004: 4);

and in statements such as these:

“Scientists were not confused. They were laughing at us at the conference,” said Achmat. “South Africa is a laughing stock - not only the health minister, all of us are.” (*The Cape Times*, 28 July, 2004)

“What government does not appreciate is the grief contained in every home, every workplace, every school across the country,” said Achmat (*The Cape Times*, 28 July, 2004).



Unhealthy political agendas which misinform are also set by reports relying on AIDS dissidents as sources for views and information on nevirapine:

It goes without saying that Minister of Health Manto Tshabalala-Msimang is doing a sterling job by encouraging the public to use garlic as well.... Garlic is cost-effective, with no toxins, and is more accessible to the poor and unemployed who are ill....

The thinking behind the Treatment Action Campaign was to persuade the government to supply the toxic anti-retroviral drugs to public hospitals and clinics (*The Cape Argus*, 6 April, 2004).

The above extracts are from an opinion piece written by a ‘medical AIDS specialist’. The article is attached in Appendix J to fully illustrate editorial irresponsibility in allowing such an unbalanced opinion to be published within the context of the South African AIDS epidemic. A response to the article was published the next month which voiced the corrective opinion of experienced medical experts, “Anti-HIV drugs do help those affected” (*The Cape Argus*, 26 May, 2004), but there is a good chance that the damage was already done and some patients either spurned ARVs, including nevirapine, or defaulted on their treatment.

At the opposite end of the spectrum, reports using scientific sources and a strong public voice, preferably that of a woman when dealing with nevirapine as a treatment for PMTCT, result in a socially educational agenda which informs on science issues around HIV/AIDS and ARV treatment including nevirapine and its benefits.

An example of such a report entitled, “The transformation of Deli Sindane” in *The Cape Argus* on 1 December, 2004, is attached in Appendix K. This article was chosen because of the journalist’s unfailing integrity and sense of public responsibility which permeates throughout. It is a feel good story which empowers through knowledge and motivates those living with HIV/AIDS. The statements are educational, positive and sing with social sensitivity. The source is an ordinary yet extraordinary woman, Deli Sindane, who puts a strong name and a beautiful face to AIDS and who

hopes that her life story will help to eradicate the stigma and silence that still envelops HIV/Aids more than a quarter of a century after the start of the global epidemic (*The Cape Argus*, 1 December, 2004: 22).

This article demonstrates that nevirapine reportage which relies on solid scientific sourcing, as well as a responsible portrayal of government and activist issues, results in healthy informative and educational agendas. Such an agenda can ensure a more positive public experience of the media representation of this life-saving drug.

The following extract reflects a journalistic sense of cultural and social awareness which produces a delicate and responsible report on nevirapine with good science sourcing and responsible activist and government sourcing. Firstly the reporter presents correct statistical information on how more women than men are infected with HIV in Africa:

In terms of infections 13.3 million women live with the disease, compared to about 11 million men

Against these serious statistics he then presents the major benefit of nevirapine:

The South African Health Review says a single dose of nevirapine given to a three-day-old infant can reduce mother-to-child HIV transmission by up to 50 %

Lastly the journalist presents a complete picture by approaching the issue of African gender inequality through an un-inflated comment from the HIV/AIDS action group UNAids:

Women and other vulnerable groups are particularly at risk of infection. Largely because of unequal status in society (*The Cape Argus*, 1 December, 2004: 22).

The report, available in appendix L, appropriately presents sdNVP within an African context: promoting the drug above all else as an effective treatment for PMTCT in a society where women, because of cultural pressure, are more vulnerable to contracting HIV than in other societies. The report, by addressing the issue of gender inequality, is educational, not only for the more challenged members of the community but also for the more empowered and privileged population who may not be aware of the cultural complexities and challenges facing fellow members of South African society.

4.3 Concluding interpretations from the recorded content analysis results:

The findings from this first phase of the fieldwork research need to be interpreted in order for some primary conclusions to be drawn. In this section the preceding discussion of the results, in terms of the expectations and research questions, is drawn together by highlighting the main negative and positive results.

4.3.1 Interpretation of the results pertaining to nevirapine reportage frequency and content direction

Results indicate that *Die Burger* covered nevirapine issues far more extensively than both *The Cape Times* and the *Cape Argus*. This may be interpreted as a more socially responsible approach to reporting on a life-saving drug especially when *Die Burger's* content direction was more positive than negative, as opposed to the other two dailies where *The Cape Argus* had a 50/50 negative/positive direction and *The Cape Times* a more negative content.

The combined content direction of all three publications was marginally more positive than negative (47 percent positive, 39 percent negative), although not positive enough to cater for the 14 percent neutral direction and push the overall positive direction above 50 percent. This combined result seems to indicate an overall lack of a “strong enough” sense of social responsibility in reporting on nevirapine which could result in, at best, a public sense of ambiguity in the reception of information on the drug and, at worst, a negative nevirapine impression.

Finally, with regard to nevirapine press coverage and content direction, the results indicate that reportage clusters around controversial events such as the 2004 International AIDS Conference (where the South African Minister of Health openly and aggressively questioned nevirapine) and the question marks over the Ugandan HIV NET 012 trial and the safety of nevirapine by the AP reports in December 2004.

This “cluster reporting” during periods of heightened drug controversy results in an erratic nevirapine reportage pattern, with a high concentration of reports portraying the controversial and politicised aspects of the drug rather than its benefits. Once again this dilutes the advantages of the drug in the eyes of the public and may well create an atmosphere of uncertainty and fear about AIDS treatment for PMTCT.

4.3.2 Interpretation of the results pertaining to the quality of nevirapine reportage as judged by various criteria

Results suggest that the quality of scientific and treatment reporting on nevirapine begins and ends with the sources used. The journalistic choice of source determines both the quality of scientific communication and the agendas set: two factors which, in their turn, determine the content direction.

The first phase of the fieldwork research yielded the information that government sources overall were most relied on for nevirapine reportage. This is also true for each individual publication.

The combined publication use of government sources spanning the selected time frame number 40. Only almost half of that number is scientific (26). Activists ranked almost as high as scientific (24) and the public trailed behind at four. The number of AIDS dissidents used as sources was also low (5).

Results further indicate that there is a high correlation between the use of government, activist and AIDS dissident sources and a negative content direction. Once again, this is true for each and every publication as is the correlation between a positive direction and the use of public voices and science sources.

This correlation pattern is reinforced in the recorded results of single-sourcing where the majority of unbalanced, undiluted reports which use only a government source have a

negative content outcome. Adversely the majority of scientific single-sourced articles have a positive content direction.

With government and activist sources together far outnumbering scientific and public sources it is reasonable to assume that the public will have a fairly high negative experience of nevirapine through the press.

This high level of negativity rests on the fact that an over-reliance on government and activist sources has resulted in a strong element of political agenda setting whereby the potential for educational nevirapine agendas has been sidelined. The high political content (not as high as the informative content but far higher than the educational content) has portrayed nevirapine as a pawn for political agendas (both in the government and activist circles) and in the process, as recorded in the text extracts in section 4.2.2ii, much inaccurate scientific information and risk sensationalism has been communicated to the public.

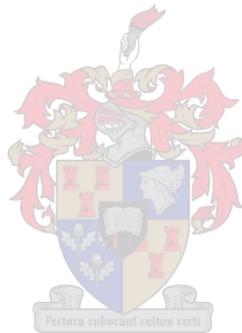
Here, once again, a lack of journalistic social responsibility is seen in the dissemination of unbalanced bad press on nevirapine. It is reasonable to expect that such irresponsibility within the context of a socially and culturally challenged community (where a lack of education and a strong patriarchal system continues to incapacitate the public, particularly women, in their abilities to make informed decisions on nevirapine) will further confuse the public about a life-saving drug.

Alternatively, it is possible that the more positive journalistic approach, which seeks an educational outcome and relies on public and scientific voices as sources, will benefit the community by giving hope for the body by promoting the benefits of nevirapine and by giving hope for the spirit by breaking down the AIDS stigma. This is particularly true of using women's voices from the community as sources when reporting on nevirapine.

In conclusion, an interpretation of the main findings from this first phase of the fieldwork research has established the erratic pattern and ambiguous content direction of nevirapine

reportage in the three dailies under study. An exploration of source and agenda setting has enabled the researcher to analyse trends in the quality of science reporting around the drug.

At this stage of the study the researcher was able to “read” into the attitude of media practitioners towards nevirapine. In Chapter 5 the reasons for a largely ambivalent journalistic portrayal of the ARV are explored.



CHAPTER 5: RESULTS OF IN-DEPTH INTERVIEWS WITH MEDIA PRACTITIONERS

The content analysis provided the foundation on which to base further correlative study, through in-depth interviews, with the environmental factors which influenced the content of the media reports on nevirapine over the specified time period.

These environmental factors consist largely of the media practitioners' relationships with and attitudes to nevirapine itself, the public and traditional news values and media policies presently practised by the publications under study.

5.1 Presentation of the in-depth interview results

The results of the in-depth interviews with media practitioners are qualitative in nature as they yield information on the interviewees' perspectives of media practice and the role and function of health reporting within a commercial news environment. These results thus explain the status of nevirapine reportage.

The interpretation of the data collected in the in-depth interviews is facilitated by primarily recording or coding the media practitioners' views which "speak to" the various categories stored in appendices M and O. These recorded results are interpreted here with the help of reference to selected editorial and journalistic comment.

5.1.1 Discussion of the results from in-depth interviews with editors

On interviewing editors of local daily papers, the reasons for the standard of nevirapine reportage were both reinforced and elaborated on. The conclusion from the previous chapter that sourcing and agenda-setting largely determine the content direction of nevirapine reportage is played out once more, and thus confirmed, through the voices of the media practitioners themselves.

This second phase of the fieldwork research process strongly supports a major initial expectation of the study:

- Clear scientific nevirapine communication is sidelined by political agenda and traditional news values

Furthermore, discussions with editors explain in more depth how and why nevirapine reportage can pose an immense challenge for those journalists writing for a commercial newspaper in South Africa.

Three editors were interviewed: the editor of *The Cape Times*, Chris Whitfield (CW); the news editor at *Die Burger*, Estelle Ellis (EE) and the science and health editor of a national daily who requested to remain anonymous (A).

The main reasons for the standard of science and health reporting on nevirapine are discussed within the context of various categories which emerged during the interviewing process.

1 Function of the media



The approach of this research is primarily functional and as such it is important to gain an understanding of how the editors, (who dictate to the journalists, the “message handlers”), perceive the function of the media in a developing South Africa. This perception may largely determine how nevirapine is reported on.

There is opinion that a South African newspaper must play a surveillance role:

In any society a media’s fundamental role is a watchdog one. A fourth estate-type function (CW).

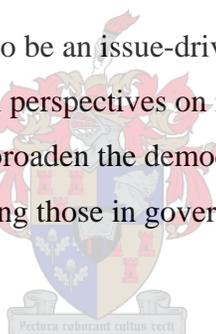
Others, however, believe that:

We are supposed to be the informers and not the judges. We need to put things out there so that people can decide for themselves. When reporting on something like HIV we must impart all the reasonable information available to us (EE).

2 News policy

Tied to the editor's perception of media function is his or her idea of in-house news policy. Both *Die Burger* and *The Cape Times* promote a democratic in-house media policy whereby issues are openly aired from different perspectives and public debate is encouraged:

Our in-house policy is to try to be an issue-driven paper. You take an important issue and reflect all perspectives on it over time and encourage debate. In terms of trying to broaden the democracy I think we are doing that: allowing people, including those in government, to reflect on different perspectives (CW);



We must be balanced and present all sides so the readers can decide for themselves (EE);

Every day brings a surprise on any given issue so I like to think the best way to judge coverage is over time and that is how you publish balance (CW).

Here it is apparent that the cause of the dissemination of misinformation on nevirapine has its roots in news policy itself where there is a conflict between reporting for a new democracy and an old one from a purely Western media policy: the old established democracies have the social structure and educational background to cope with debate on

an issue such as nevirapine, whereas fledgling African democracies like South Africa, which is socially challenged on the educational and cultural fronts, do not.

3 News values

This idea of public free choice through a wide range of perspectives made available through the press is reflected by editorial views on news values:

I'm talking broadly now about news values: I want to be a paper that gives information that you can use to make decisions about your own life (CW).

Even with these best of intentions, however, the commercial element creeps in and the “democratic” goodwill appears to evaporate somewhat:

The only injunction I have is that *The Cape Times* is pitched at a certain readership level: aspirational. We aim at more or less the middle to top end of the market. There is a commercial imperative there. Are we elitist? I'm sure we could do better (CW);



One of the more justified criticisms against *Die Burger* (and perhaps other Western Cape papers, particularly perhaps the *Cape Times*) is that we ignore what may interest middle class people – we keep the marginalised communities marginalised. Which we try to change but which is difficult because we are a commercial product. So we need to give our readers what they want to read (EE).

As a result of “the must sell” element in the media, important health issues such as information on life-saving drugs, are sidelined:

Maybe because we don't present our health reports in the newspaper as we should: often they are ‘hidden’ inside somewhere instead of making the

lead story on the front page. They are treated as softer stories, even significant breakthroughs cannot stand up against commercial news values where murder or accidents take precedence (EE).

There are indications, furthermore, that the commercial news value aspect is becoming ever-more demanding which, ironically, diminishes journalistic freedom:

In a way I do think the news values have become more commercially driven in the last five to six years. We are much more aware that the paper is not there so we can exercise our journalistic freedom the way we want to. There's a very strong commercial element. And I think this plays a large role in determining what goes into the paper (EE).

The negative outcome that this has for nevirapine is obvious and a cause for concern:

If I can put it like this: Nevirapine became a political issue rather than a health issue (EE).

It seems that the fact that nevirapine has become primarily a political rather than a health issue explains the cluster reporting around controversial nevirapine events such as the International AIDS Conference in Bangkok. The commercial news value system hones in on a controversial drug and the elite voices of political authority, almost against the integrity and will of the reporter, are shouted loud and clear in dailies across the country for days:

We do as the media feed into this in a terrible kind of way and there is the inherent tension of "Oh God here we go again, the Minister is questioning the drug, we are at the beginning of yet another political row, maybe we should just ignore it". But that isn't really our job. She is a publicly elected official and we do have a responsibility to report what she says even if it is nonsense (A).

One of the recorded comments indicates, however, that it does not have to be this way:

The Daily Mail, on the other hand, has done a turn around campaign in the last eight years: they are a magnificent paper, for women specifically.

They have turned the traditional news values system on its head. If there is a breakthrough in breast cancer, for example, *The Daily Mail* will lead on it. If I could get them to do that on this paper you would have to buy me a really big bottle of champagne! (EE).

4 The role of the journalist in reporting on nevirapine

From the perspective of a science and health editor the complexity of a drug like nevirapine cannot be underestimated. Its potential for resistance as a single dose and toxicity as part of a combined ARV drug regimen render it highly controversial and vulnerable in the hands of those writers who do not understand it. When reporting on nevirapine this editor warns:

Be careful. Be very careful. Nevirapine is an intensely controversial drug in South Africa, so uppermost in my mind is to be careful and this means whom I go to for comment and how I write my story and how much context and background I get for my story. I might, for example, write far more for nevirapine than I write for other AIDS drugs. I don't write about all the other ARVs in the same way that I cover nevirapine (A).

It is also recommended that journalists carry their responsibility right through to post-submission of their report:

I would also be careful that whoever edits (a news editor or sub-editor) my copy at the other end is aware of the nuances around this drug. I put a note at the top of my story which will say 'please phone me if you want to

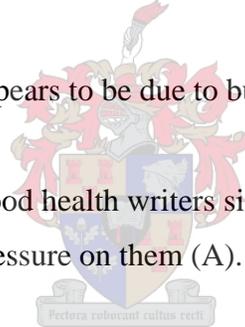
change the wording here, it is really important.’ Or ‘please call me if you want to change the story as it is a very technical piece’. I don’t need to do this for every story I write (A).

This sense of responsibility, alas, is not very widespread:

In the many news rooms I have worked in my experience tells me that 10 years ago people were very dedicated and actually appointed AIDS writers to write just about AIDS. But today, due to staff shortages, AIDS writers have had to become health writers: health is such a wide field and AIDS subsequently becomes marginalised. The pity is nobody fought for AIDS reporters. The international news agencies like Reuters are doing much better work on AIDS than we South Africans are ourselves (EE).

A lack of quality reporting also appears to be due to burn-out:

I think a lot of the really good health writers simply burn out and leave because of the immense pressure on them (A).



5 Sources

During the interviewing process with editors a substantial amount of concern was raised over the danger of single-sourcing when reporting on nevirapine.

The article ‘Government welcomes US nevirapine doubts’ (*The Cape Times*, 16 December, 2004) is attached in Appendix N and is used as an example to illustrate the danger of single-sourcing:

This is a single source story which comes from a Sapa wire which means they have not gone and checked with any of the organisations quoted how accurate this information is. Now, with a politically-sensitive drug like

nevirapine, you need to know that government spins on this one, so you should actually go and check that this is indeed correct. The information in here is not particularly accurate: it is the kind of story that would make me very worried if I was an HIV positive mother who was shortly to give birth and was contemplating nevirapine (A).

Another example of the danger of relying on government as a source for nevirapine reportage is seen in the science and health editor's Bangkok experience where Precious Matsoso, the MCC registrar, told this editor they were considering banning nevirapine. The story was written and the writer was lambasted the following day for misrepresentation when Matsoso said she never suggested this. In the words of the editor:

The generous interpretation of this is that there is a naivety on her part in dealing with the media, the alternative explanation is that this is done with malign intent: they know that if they drop these things in it'll cause more harm. I think it's more clumsiness (A).

The above examples are not isolated events as there is another editorial opinion that the problem is widespread resulting in a lack of unbiased, pure clinical and treatment information on the drug:

I think that there is a lot of single-source reporting on nevirapine in South Africa. I think that completely objective and complete reporting on nevirapine is very scarce. There is a whole field of reporting on how and why the drug should be taken which has not been done (EE).

Single-sourcing or an over-reliance on political sources such as TAC and the government may also be due to a scientists' reluctance to speak with the press:

Scientists are known as dismissive and they are also sick to death of this issue and I think they are really, really, really tired of talking to the media

and I know that a lot of them feel that what they say is distorted, poorly understood and does more harm than good. This is true of the AIDS dissidence and the nevirapine debate. There are scientists who have just stopped talking to the media (A).

6 AIDS dissidents and nevirapine

Tied to the issue of sources is the dilemma posed to media practitioners about whether or not to report on the views of AIDS dissidents when they have something to say about nevirapine. Some editors take the issue very seriously and approach it with all journalistic antennae waving:

This is an issue that I have really grappled with in the last year or so; in fact I have had sleepless nights about whether to write stories about them. My feeling is that we don't give airtime to quacks and cranks. However, when the cranks have the ear of government, when the cranks have the ear of your Minister of Health and your President, then we have to write about them because we need to know who's influencing the people who develop the policies that affect our lives (A).

The public undoubtedly has the right to know who the policy makers listen to but it is the media's responsibility to portray AIDS dissident views in an extremely balanced manner with serious consideration given to who the readership is:

Given that, there is a huge issue on how you report on a story like this. We have a lot of discussion on how to write it. The decision we make is also based on the fact that our readership is sophisticated and relatively well-educated and therefore able to draw its own conclusions. A lot of thought goes into how to report it (A).

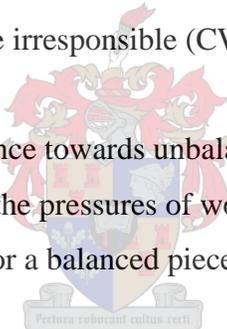
This is echoed by the news editor of *Die Burger*:

I think AIDS dissidents should, cautiously, be given an opportunity to voice their opinions in the media. I don't think it can do that much damage. I think it must be handled cautiously, but I don't think we can ignore the views of not that small a part of the community (EE).

Other editors appear less concerned about an unbalanced communication of AIDS dissident views:

I think it is absolutely fair to put forward AIDS dissident view points as well. Freedom of expression is fine as long as it doesn't cross the boundary and become hate speech. If we were to reflect dissident views repeatedly, and allow it to become a mainstream coverage on the issue, that would be verging on the irresponsible (CW).

In addition to an editorial ambivalence towards unbalanced dissident reporting (as long as it doesn't verge on "hate speech"), the pressures of working on a daily paper where news moves fast does not always allow for a balanced piece and may exacerbate the presence of pure dissident views:



The problem with news is that it is such a fluid thing: A dissident says something, you try to get hold of TAC to get their view but they are not available, [but the story has to go], so the AIDS dissident stories are not always balanced by a science take (CW).

7 Relationship between media practitioners and consumers within the nevirapine context

There is editorial opinion that the relationship between the public and health journalists with regard to nevirapine is under-developed and lax:

We have left it to the political writers; there are very few health and human interest writers who have picked up on the issue of nevirapine. I think what has happened is that the political writers have been covering it so much that the health writers have been sidelined (EE).

This unhealthy relationship between readers and writers with regard to nevirapine is spawned by the problem of understaffing and the very nature of news itself:

Reporting on nevirapine is not consistent because a health reporter on a daily has to cover so much: that is part of the reason. The other part is because the media is very reactive: we are event-driven. This is the huge problem (A).

The politicisation of nevirapine has erased, to a large degree, the human side of nevirapine: the real stories that people can benefit from:

One of my long-term plans is to get the human story out, because it could literally save lives. It hasn't been done. This is an indictment against the media, because they have left it [nevirapine] to the political reporters and the health reporters have actually done very little (EE).

This educational lack in the press may have dire consequences as there is the view that the public does not rely on the newspapers as a reliable source of health information and instead turn to other dubious sources:

It is a process: in SA journalism we are stuck because we've been faced with this huge tide of crime and volatile politics which have pushed everything else out from the first five pages. I think this why people may not use the paper as an important health source, because it is just not there or if it is it's a week old already because it was just rolled over every day

until they could find space for it. Thus I think *Huisgenoot* or *You* becomes the primary source of (mal)information (EE).

The belief that the public does not rely on the media as a science and health source is echoed by the editor of *The Cape Times*:

No. I would be very, very surprised if the public relied on the media as a source for health information. I think that if they saw something in the paper relevant to *their* health they might then query it with their doctor (CW).

In spite of editorial belief that the public does not use the media as a health information source, there is a general awareness of the plight of women who struggle within the confines of the patriarchal culture:

Yes I think South Africa's patriarchal society does influence the spread of HIV (EE).



And:

I think we have a very unfortunate circumstance in this country: historically it is very patriarchal. I think the majority of women in this country live in unfortunate circumstances and I think there is a hell of a lot to be done (CW).

Yet, in spite of this awareness there appears to be a lack of reporting commitment to it:

What we see is the absence of consumer-driven lobby group for health in general. This affects how we report and where we get information from. This also means we don't think enough of how our readers interpret the stories. I tend to think of my audience as policy makers and business people; even so if

I'm writing about a drug, maybe they are interested in it for their mother or sister. We probably should think more about those consumers (A).

8 Recommendations for the improvement of science and health training

There is reason, however, to hope for an improvement in the relationship between writer and reader. Editors are ready to offer suggestions on how to make the media consumer more visible to the reporter and thus enable the print media to offer more to those who need health information on nevirapine.

These suggestions include improving the science in health writing:

I recommend the use of science writing courses. Most definitely, I don't think you could recommend it highly enough. Because you are not going to find a scientist applying for the job; so you have to look for the right personality to cover that area and then I would most certainly recommend that he or she be trained (CW).

As well as keeping tabs on journalistic ability on how to report on the science around HIV/AIDS issues, there is also editorial intent to dress these reports in such a way as to appeal to the receivers:

My ideal, and I want to introduce it here, are narrative science writers. In America, for example, they have science writers who are brilliant narrative writers. To me, with our strong tradition in South Africa of telling stories, this is how we must do it. I think reporters must therefore be trained in narrative writing as well as in science writing (EE).

Within the context of nevirapine and its benefits for women who are challenged both in body and spirit by their own culture, there is ample opportunity to draw on the voices of women as story sources and in so doing educate and empower:

We can empower women through our writing. I think the women in this country are wonderful, they are very strong. I think the media still portrays them wrongly by putting them in the paper as victims and not victors. I think we must portray them as survivors: South African women are survivors and I think they are really fantastic. So we are not distorting reality by portraying them as such. And women like reading about other strong women (EE).

It is necessary, if all South Africans are to move forward together, that we are all aware of the challenges involved for everyone:

I firmly believe we have to write about whatever is happening in Khayelitsha even though nobody there will ever buy *Die Burger* to read it. But the people who read *Die Burger* must know what's happening there because technically speaking it's their community (EE).

Even though there is sentiment that the poorer communities will not buy the more commercial papers, it is not said that they will not benefit indirectly from the true nevirapine story because:

I feel that if the right angle is taken, the right message will filter down to those people who don't even actually buy *Die Burger*: people put the articles up on the walls or maybe somebody buys it only once a week, and then there must be something in it (EE).

5.1.2 Concluding interpretations of results from in-depth interviews with editors

It seems that the editors are well-intentioned in promoting democratic publications.

This democratic element is reflected in the media function and news policy views of the participants who see it as important to put forward a diversity of view points from which the public can be informed and make their own decisions.

It is important to note here, however, that these views may not be the best policy for those members of the population who are most affected by HIV/AIDS and need unambiguous information on life-saving drugs such as nevirapine. The reason for this is that those affected are generally not educated enough to filter out the detrimental views from the democratically presented diversity of opinion.

Furthermore, if the function of the media is perceived to be that of a watchdog role, as is the case with *The Cape Times*, the danger is that the focus is very much on government: a fact which leaves less than less space for clear health reporting.

It is within this context of surveillance that a drug like nevirapine which is highly controversial, and has thus been used as a pawn for political party brownie points, is portrayed more from a political perspective than a health perspective.

This over-politicised trait in nevirapine is exacerbated by:

- Commercial news values which push for nevirapine portrayal into a more sensationalistic light or, if it is reported on from a treatment perspective, relegate it to the middle pages in favour of hot-selling leads on murder, crime and political scandals
- The fact that news, by its very nature, is reactive rather than proactive: rather than reporting on the clinical benefits of the drug, it is far “newsier” to hone in on the latest argument over nevirapine between the Minister of Health and TAC
- The fact that health reporters have allowed themselves to be side-lined by political reporters over nevirapine

- Linked to the above, health reporters are over-worked and do not have time to honour pure health reporting on nevirapine.

Thus an inherent sense of social responsibility can be easily swallowed up by the commercial news value system, a system which puts incredible pressure on its reporters to produce “hot” items in time to sell.

It is here that reporters lose touch with their readers and do not give them what they need: sadly, health issues become dangerously compromised within the commercial news structure: daily deadlines become deadly deadlines if, for example, rushed single-sourcing (because scientists can be inaccessible but AIDS dissidents, politicians and activists are always ready to prostitute their views) produces scientifically unbalanced reportage that may discourage a potential nevirapine user to dismiss the drug or a user to default on treatment.

All is not doom and gloom, however. News policy and news values can be adjusted to accommodate important health issues: as is seen in the example of Britain’s *The Daily Mail* where breaking health issues can lead above politics and violence.



Further hope lies in the raw material offered by South African and African culture where the tradition of story telling can be used in narrative science writing to educate on HIV/AIDS issues including nevirapine. Journalists can be encouraged to use the voices of African women who have survived to generate more positive and educational human interest stories.

In short, the constraints for reporting in a balanced manner on health are significant where commercialised news values beg for easy newspaper sales and, in the process, cheapen nevirapine reportage at the expense, ultimately, of the public.

The challenge to give the pure science on nevirapine via a positive educational agenda is thus immense, because a newspaper does depend on commercial news values to keep

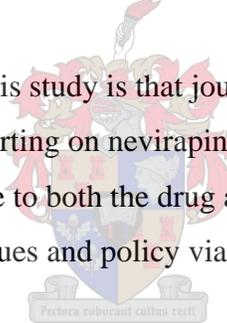
afloat in a competitive media market. If, however, the relationship between health news consumers and health journalists is to improve, the challenge must be taken on through an adjustment of news values and policy around health reporting.

5.2 Presentation and discussion of results from in-depth interviews with journalists

The interpretation of the data collected in the in-depth interviews with reporters is, as in the case of the editors, facilitated by primarily recording or coding journalistic views which relate to the various categories stored in Appendix O. These recorded results are interpreted here with the help of reference to selected journalistic comment from the stored information.

5.2.1 Discussion of results from the interviews with journalists

One of the major expectations of this study is that journalists are not aware of the vast responsibility they carry when reporting on nevirapine. In order to explore this expectation, the journalists' attitude to both the drug and to the public is analysed within the context of current day news values and policy via the criteria as presented in the categories below.



Once again these categories incorporate certain research questions central to the study, such as the use of sources and subsequent agenda setting, accurate science reporting on nevirapine and the handling of ethical issues such as portraying the public as victims within a nevirapine context.

1 Perceived journalistic function in nevirapine reportage

As a whole, the participants demonstrated highly ethical perceptions for when reporting on nevirapine.

These perceptions ranged from getting as much information on treatment out to the public in an accessible way in order to curb the spread of AIDS:

Give as much up-to-date information as possible on treatment for the prevention of PMTCT. I think it is also important to investigate other treatment options (KC);

I feel I have two roles: to enlighten people on issues they knew nothing about before and to educate them. I see it as important to break down the blue sky science, and it really is as far removed as blue sky science to some people because they just don't understand it at all (DC);

to a heightened awareness of the dangers of presenting nevirapine from a political viewpoint:

I think of how political nevirapine is. You are far more aware of this than when you are reporting on other ARVs. You know that what you say is going to have a political consequence. So maybe what happens is that you oversell it, to a certain degree you become a nevirapine crusader because you know it is a good drug and that nobody in the scientific community denies this. You don't want to become one of those activist journalists but just by being true to scientific respectability (which is vital to health reporting) you automatically step into the arena of political activism (JV);

The other side is the political aspect. I do a lot of analytical stuff on the controversial issues. [Normally] as a journalist you present different sides of an issue and thus let people choose. But with things like this, where people will die if they stop their ARVs, you have to have more of an activist role. I feel this social responsibility greatly (DC).

2 Sources

This sense of social responsibility is further reflected in the health writers' approach to and awareness of the pros and cons of various sources. This is seen in their desire to rely primarily on science sources and avoid those which may present a more political agenda:

I never use a study unless it is peer reviewed and I check up on the person who wrote it. I would never submit a story on nevirapine without first passing it by a science source I trusted (WB);

If I don't understand things I always ask the scientist, because I cannot run the risk of passing on flawed information (DC);

When I use TAC as a source I find my writing becomes drawn into a political debate. They are at the forefront of the politicisation of AIDS, they do have a very politicised angle to things because this is their cause (DC).

But the realities are that the use of good scientific sourcing in nevirapine reportage is compromised by the commercial and thus largely political news framework of today's media policy:

AIDS is such a political issue, nowadays if you are health reporter you spend time in parliament and go to political rallies because the big story is a political story. I probably speak more to the health spokesperson of government and the health spokesperson of the DA than our political reporters do and I don't think this is the way it used to be. It's just AIDS that does that (JV).

Not only does policy interfere with the portrayal of pure science around nevirapine but also the pressure of meeting deadlines lures journalists into presenting a political agenda:

Because reporters have daily deadlines they use information that is spoon fed to them or that is easily available. And they are not critical enough of that information. For example, if TAC said something it was immediately seen as good and journalists just kind of accepted this, I did it as well. TAC *are* the good guys, but at the same time a lot of the media had lost their ability to analyse critically what they were saying (WB);

Health writers use TAC because of their accessibility, not because they would rather but because they have a deadline to meet. They are very outspoken and they are almost like rent-a-quote, they do give fantastic quotes. If you are working on deadline this is very appealing: let's just get TAC (DC).

A critical use of TAC as a source in nevirapine reportage is also to be considered when depicting those affected by and living with HIV/AIDS:

Much of the community voices get channelled through TAC before they get to you, which is not really then the pure thing. This is definitely a gap in my reporting which I need to address (JV).

There is strong journalistic sentiment that the use of the public as a source humanises the AIDS story and saves it from becoming mundane:

I use the community as often as I can, otherwise the story is too bland: you have to put a face to it (WB).

There is also, perhaps, the need not to overuse the voice of a mother when reporting on nevirapine:

A mother's voice is a very emotional one "you saved my baby": there is nothing more powerful. But this is a limited voice you can use because the angles are limited (DC).

3 Journalistic opinion on the media as a true reflection of reality for the public and as such an important science and health source for the public

The journalists' heightened sensitivity to the use of sources when reporting on nevirapine is explained by their unanimous belief the public, on the whole, does believe the information they receive from the media:

Yes, I think they do believe what they read and I think that that is what makes it so intimidating. Reporting per se must always carry both sides of the story; but with ARVs there is the obligation of scientific authority. If you report on something which is not scientifically respectable you cause a lot of damage, especially in health writing where it a question of life and death. People will believe what you write (JV);

According to studies, as far as I have read, up to 70 % of them believe what they get from the radio (KC);

I think they probably do [rely on the media as a source of health information] if you are talking about all media, especially radio. This is why it is so important to do the job well: these people do not have any other access to the information through the Internet, libraries etc. Or maybe they are simply not educated enough to go and seek out the information for themselves. These are the poor people who will sit in line all day at a clinic to get treatment from a doctor who is not going to give them an extra second of their time to explain things in detail. So where else are they going to get their information from? Either from the media or

other people who have, perhaps, got their information from the media and so on (DC).

There is therefore concern that the politically exploited controversial nature of nevirapine is detrimental to the media audience as:

I think that they are often very confused by the mixed messages they receive (WB).

4 Should the opinions of AIDS dissidents be voiced through the media

It is because of these confusing mixed messages that reporters approach the issue of whether or not to cover AIDS dissidence with extreme caution and responsibility. There are those reporters who would prefer not to cover the issue at all:

I think it's a very thin line. Coverage of them glorifies these dissidents, even negative coverage is coverage. The less you write the better. We report on the weird things that Manto and Mbeki say about AIDS and the public then has a very confused impression, they think this is the honest truth: this is seen from the raping a virgin myth - people took it seriously even though it was reported as a myth. It is a sensational take (WB).

Some journalists feel that, due to the demands of democratic media policy (that all views be presented), AIDS dissidents should be granted coverage, albeit in a highly selective and contextualised manner:

As a health writer you have a responsibility not to spread this, at least not any further than you would have to: we would have to report on Rath walking down the street handing out his vitamins, if this was the case. But a way around it is not to report on it straight but to get other people to comment on it and give it context. You cannot say 'I am going to report

everything I hear', because you may create damage by being completely unbiased (DC).

There is, however, the opinion that even by presenting a dissidence view in a “biased” way, the journalist still runs the risk of creating damage:

For example if you report on ARVs as the best treatment available for AIDS and then also put across the opinion of an AIDS dissident like Matthias Rath: by the standards of political reporting you would be acting ethically but you would really be causing a hell of a lot damage. Even if you report what Rath says, and then shout it down immediately afterwards people have already read that and actually got stuck at what he said (JV).

5 Reporter relationship with the media audience

It appears that all the journalists interviewed are aware of the social challenges facing those members of the media audience living with AIDS. This journalistic sensitivity to the disempowering effect of a lack of sufficient schooling and thus a public tendency to believe and be easily misled by conflicting media messages, enforces a health writer's sense of integrity in a desire to select socially responsible sources.

A journalistic awareness of the particular cultural challenges women face in addition to the social challenge of a lack of education is very strong:

I think the majority of women in SA are unfortunately not reaping the benefits of gender equality as seen in on government level and I think AIDS is pushing this back even more (JV);

Yes, AIDS is spread amongst women via cultural inequalities. I feel a lot of sympathy for them (WB);

Women have so little choice in terms of their sexual relationships. It is, therefore, important to do gender and culturally sensitive reports. To give those women a voice is a most fantastic thing. When the men learn their woman is HIV positive, they leave them on their own to bring in the money, look after the children etc. This affects every facet of their lives: how they work, where they live, future relationships. They are definitely carrying the burden, no doubt about it (DC).

The struggle many women face in their daily lives, however, does not instil a negative perception of them in most of the reporters who want to portray them mainly not as victims but rather as fighters and survivors:

In this country women are the unsung backbone of community life and raising families. They are economically and culturally disadvantaged but they are the ones who hold communities together (KC).

The women involved in township workshops are such a strong bunch: they would turn this country around in no time, if given the chance. They just put their heads down and do what has to be done (DC).

As strong as these women are, however, their plight is often harder for others to bear and a lot of the highly committed health reporters often burn out and abandon their jobs and, consequently, those very people they were trying to encourage by promoting their strengths:

I think there are some very good health writers in the country, but a lot of the good ones have actually left the country. They have enough and go: it is a heavy job because it can be very emotional, especially when you are dealing with AIDS issues and some journalists just can't take it any more. The voids are then filled with people who do not know enough and this is dangerous (DC).

6 Journalistic knowledge of the science around nevirapine

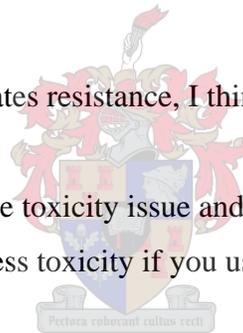
It is true that although the intentions of health writers are sincere, their scientific knowledge on complex drugs such as nevirapine appear to be not quite good enough and that the voids left by the exceptional writers are indeed sometimes “filled with people who do not know enough”.

A brief discussion on the extent of the journalists’ scientific knowledge on nevirapine reveals why inaccuracies may occur in nevirapine reportage.

Most journalists were aware that it is single dose nevirapine which can create resistance and nevirapine as part of a combination therapy which causes toxicity, although one journalist was unsure:

Single dose nevirapine creates resistance, I think (JV);

and one appeared confused over the toxicity issue and stated that single dose nevirapine caused toxicity and that there is “less toxicity if you use more drugs”(WB).



With regard to the clinical action of nevirapine there was uncertainty and error with one journalist admitting:

No I am not comfortable in my knowledge of how nevirapine operates (JV);

and others confusing the treatment process:

It interacts with the transfer of the virus during the birth. So as the baby is coming down the birth canal it interacts at that point, then the baby is given another dose ten days later which will then “mop up”, basically it’s a mop up arrangement (DC);

The baby gets spoon of nevirapine syrup within 24 hours of birth and the mother gets a dose when she goes into labour (WB).

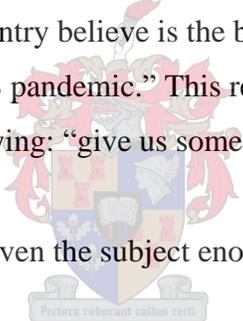
The above two statements incorrectly describe when the baby receives a single dose of nevirapine which is within 72 hours of birth.

Overall journalistic attitude to sdNVP as an effective treatment within an African context is on the whole positive:

Dr Glenda Gray from the Chris Baragwanath Hospital said to me:

“Nevirapine may not be a first class ride for HIV positive pregnant women in South Africa, but it is an economy class ticket that scientists and medical staff across the country believe is the best chance in beginning to address the paediatric AIDS pandemic.” This really meant something to me because people were saying: “give us something” (DC).

One journalist, however, had not given the subject enough thought to have an opinion on it:



Single dose nevirapine in as a treatment in South Africa? I'm not well-enough informed to tell you that, I would have to refer to a specialist first (JV).

Within the context of these results there is a journalistic awareness of the shortcomings of South African health writers:

When you are a health writer people think you know everything but you don't. It's not like in America where scientists or doctors become health writers, we don't have this in SA and it is a huge learning curve to cover health, especially with AIDS (DC).

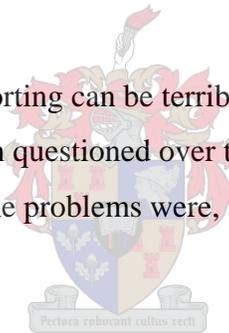
7 AP reports

With regard to the Associated Press portrayal of the question marks over the Ugandan HIV NET 012 trial last December, one journalist was unaware of the controversy and the other three were of the opinion that the reporting was irresponsible:

It caused a lot of unnecessary alarm: there were administrative problems – there was nothing wrong with the efficacy of the drug (KC);

It was a shame because it set the debate back. I know the problem was more an administrative, procedural problem which did not affect the validity of the study (JV);

I think that that kind of reporting can be terribly irresponsible. Although the HIVNET study has been questioned over the years medical experts have always supported it: the problems were, after all, administrative (DC).



There is opinion that the pressures of working on a daily paper once again had something to do with the damaging outcome:

At the same time I sympathise with the journalists because the NIH are hard to reach for comment and the journalists probably had to run the story for deadline. I have a deadline for tomorrow and need a comment from the NIH and if they don't come back to me I will run the story anyway (KC).

Whatever the source of wrong information however, the outcome is serious:

It's all very well getting a front page story saying the study was flawed but when mothers refuse to take the drug you are doing the whole world an injustice, these kind of stories *have* to be balanced. Within the context of a pandemic like AIDS irresponsible reporting like that really does not help at all. Maybe you can report like that with other things but not HIV/AIDS (DC).

Not only is the more uneducated public in general easily misled by thoughtless reporting such as in the AP reports: health journalists themselves are easily put off a solid scientific clinical trial which is still trusted in the highest of medical circles. This is evident not only in the fact that local reporters last December followed suit from the AP reports by also misrepresenting the information pertaining to the Ugandan trial, but also in comments such as the following:

You would not be able to use those findings with confidence now because of what went wrong there which is a shame. I don't know enough about it but I know I wouldn't go around quoting that study now (JV).

8 Science writing training for health reporters

In order to further understand the standard of reporting on nevirapine in South Africa the journalists were asked how much science writing training they had received.

Some had received none at all:

None. I am self-taught (KC);

No I have done no science writing training: I have been learning on the job. The newspaper does not pay for me to go on anything, but sponsored workshops have been arranged by major pharmaceutical companies for example (JV).

While others were fortunate enough to be in the right place at the right time to receive some training:

The paper does not offer health writing courses but I was lucky: Before the 2000 Durban AIDS conference a pharmaceutical company ran an AIDS information course for journalists. This really formed the basis of my knowledge about the disease and equipped me to write about it (DC).

9 Recommendations from journalists for improved reporting on nevirapine and other health issues:

One of the journalists interviewed believes that a science background at best and a general training in science writing at the least is imperative for any health writer within a South African context:

I think Tamar Kahn is the best health writer around thanks to her scientific background.³ In fact I think she is the leading science reporter in the country. I got into health writing through the Arts. I think there should be a general science-writing training for all journalists as even editors don't understand what a peer-reviewed article is, or what the difference between a bacteria and a virus is. The idea of a science desk is totally unrealistic in this country, so all journalists need a basic training in health/science writing (KC).

There is a strong recommendation for more pure science reporting and a more analytical approach to AIDS issues like nevirapine and a need to work around the politics and the stress under which health reporters work:

³Kahn has a BSc Honours in Physics and a Master's in Science Communication

There's a need for more in-depth feature writing, research and development issues. We are trying to get around to that but it is hard with the workload you have as a news reporter in this country. You have to sell it as having some political implication which is a shame as it would be nice if we could do more pure science. That's the reality we are dealing with at the moment (JV).

A possible way around the politicisation of AIDS issues and over-worked health reporters, two factors which obviously affect the final quality of health and science reporting, is the appointment of reporters who cover AIDS issues only:

I don't think you can have people reporting on AIDS and other health issues, you need specific AIDS reporters (WB).

Here again the sentiment that interference from editors can have a negative impact on the quality of science reporting is voiced:

I think your news editor should have much less control over what the health writers write, much less than with other less scientific subjects because often they just don't understand the issues (WB).

And the issues are indeed great:

Health can be a mine field to work with for somebody who doesn't know what they are doing. Because health is such a huge area with diverse aspects: the political, the health, the research, human interest. I feel as though I am constantly chasing my own tail.... It's a huge responsibility to write about HIV and I don't think just anybody should go out and do it (DC).

At the heart of this social responsibility is the educational role journalists can play:

We should be doing more story-telling, more features, we need to work on that, so people can share and learn from each other by providing positive role models(JV).

5.2.2 Concluding interpretations of results from in-depth interviews with journalists

The main findings, both positive and negative are outlined and interpreted below.

One of the major expectations of this study was that journalists reporting on health were unaware of the vast responsibility they undertake when writing about nevirapine. The results from the content analysis appeared to verify this in the high negative content direction of the texts under study. Results from the interviews, however, indicate that the reporters are surprisingly sensitive to the challenges imposed on their public within both the social and cultural context.

This sensitivity is reflected in their desire to use scientifically sound sources and to promote educational and pure science agendas when reporting on nevirapine. Even though the journalists know that the majority of those living with AIDS will not buy the commercial papers they write for, they strongly feel that the right messages, either by word of mouth or through stories displayed on clinic or township workshop walls, will filter down to those who need the information.

Furthermore all the journalists interviewed believe that the public actively seek and depend on the media for health information, a fact which seems to render the reporters all the more sincere in their desire to get the right messages across.

Their awareness and sincerity is reflected in their various recommendations for improved science reporting on AIDS and controversial health issues such as nevirapine.

Ideas for improvement include a more analytical, science-like approach to writing about nevirapine so that there is little or no room for political lobbying and the portrayal of incorrect information; an emphasis on features which once again provide context; a stronger use of the affected community as a source so that stigma is broken down and people can learn from one another; the use of writers who cover AIDS issues *only*; general science writing training for all health reporters.

Further results explain the apparent non sequitur between the negative content direction of the researched reports and the health writers' highly ethical desire to source correctly and set the right agendas to promote the curb of the spread of AIDS through PMTCT.

Opinions and feelings expressed during the in-depth interviews with the four journalists indicate that reporter ideals are not reflected in the printed content largely because of the constraints of working in a commercial newspaper environment. The content and quality of pure health reporting is compromised by:

- The watchdog role the media plays where “the big story is the political story”
- Commercial news values where negativity (such as murder, crime and scandal) is often promoted above positive educational health agendas
- Under-resourcing where: a) health writers are often denied the necessary general science-writing they need to report on health issues accurately and b) health writers burn out because they have to cover AIDS issues as well as the myriad of other health matters thrown their way every day. Their empty seats are then filled by untrained reporters who then have to negotiate their way around a health “minefield” and inevitably set off unexpected landmines which can seriously maim their readers
- The pressure of meeting daily deadlines and thus being tempted to use easily available sources such as “rent-a-quote” TAC who automatically set a political agenda. As a result little or no context is provided as reporters with deadlines do not have the time to seek out contextual information. Linked to this is journalistic inability, through lack of time and/or training, to track down extensively peer-

reviewed material and make the distinction between text book science and frontier science. Frontier science is less reliable in its position at the start of the ongoing scientific research process but is often quoted as fact by journalists who are unable to recognise that the primary stages of research are *not yet* scientific knowledge but mere initial claims that have been made (possibly from an imperfect and subjective researcher's point of view). Henry Bauer's model of the "knowledge filter" explains this phenomenon whereby frontier science passes through various phases of peer review from primary literature to secondary literature to the final stage of textbook science:

textbook science is very reliable. It's been cleansed of most of the personal bias, error, and dishonesty that may have been there originally... This knowledge filter illustrates that it's peer review, and the awareness of peer review, and the passage of time that makes scientific knowledge non-subjective and reliable (Bauer, 1995:2).

The above points support and reinforce the findings from phase one of the field research and another major expectation of this research: that the delivery of true scientific knowledge is compromised by political agenda setting and commercial news values.

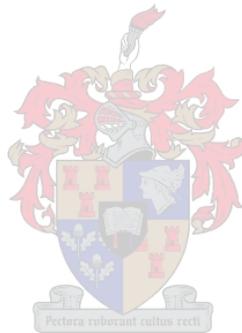
Another negative finding of this phase of the field research is that the journalistic scientific knowledge on nevirapine is not up to par and that the editor's lack of science knowledge allows these inaccuracies to slip through to the public. This again supports the research expectation that the science reporting on nevirapine, when it does occur, is often flawed and reinforces the recommendation for general science writing training for all health reporters in South Africa where, unlike in America, scientists often become health writers.

Another reason for the presence of flawed scientific and treatment facts on nevirapine, is the presence of AIDS dissidents' views in the newspapers. Although the more socially responsible nature of the reporters balks at writing about the opinions of AIDS

dissidents it is something they feel compelled to do within the context of a democratic news policy where the politically correct thing is to allow all voices the freedom of expression.

Overall the results from this phase of the research seem to indicate that reporters with socially responsible intentions are highly challenged in attempting to fulfill a socially responsible role within a health reporting context from within a media system which promotes commercial news values.

The extent of the damage is assessed in the next chapter which discusses the media audience's experience of nevirapine reportage.



CHAPTER 6: RESULTS PERTAINING TO THE PUBLIC'S EXPERIENCE OF NEVIRAPINE REPORTAGE

The first two phases of this study's field research analysed the content direction of the selected nevirapine newspaper reports and attempted an understanding of the reasons behind the standard of science reporting therein. These two phases allowed the researcher to suggest how the public may experience the high political content of the media's portrayal of the drug: namely that those most affected by HIV/AIDS would have a negative or confused perception of the drug and not fully understand its benefits, risks or necessity.

This third and final stage of the field research explores the public's perception of nevirapine reportage through the eyes of both AIDS specialists who work very closely with HIV positive women and a selection of these women themselves. This stage of the research "tests" the researcher's initial arguments as to how the public, particularly HIV positive mothers, views nevirapine as it is presented in the press.

As this section of the study is a tentative exploration of the reaction of the public to the media's portrayal of nevirapine, and as such a fairly small number of participants were involved (two medical specialists and one focus group study of 11 women), the results are recorded and presented simultaneously in the form of a general discussion which draws on the comments of the participants to support the researcher's interpretations.

6.1 DISCUSSION OF THE DOCTORS' PERCEPTIONS OF NEVIRAPINE REPORTAGE AND HOW THEY PERCEIVE THEIR PATIENTS TO EXPERIENCE HEALTH REPORTING ON THE DRUG

Doctor Inge Paschke (IP) works in the South African Public Health Sector and is involved in ARV drug administration in Paarl, Malmesbury and Stellenbosch.

Doctor Mitchell Besser (MB) is the founder and medical director of The Mothers' Programmes, an NGO which "uses education and empowerment as tools to prevent mother to child transmission of HIV, support a mother's adherence to medical treatment, and reduce the likelihood of AIDS orphans" (www.mothersprogrammes.org).

Both doctors were interviewed in an attempt to have a scientific take on:

- the quality of nevirapine reporting
- how their patients perceive a media portrayal of the drug

Besser and Paschke are both of the opinion that the media plays a very large role in determining the public's perception of nevirapine because the public does turn to the media for health information:

In Mpumalanga, where we run some programmes, there is a community called Draaifontein, where there is *enormous* resistance to nevirapine because of the messages put out by the government which have been represented in the press. These messages have come down to the people who now see this as a toxic drug. I think it is prevalent there and not here because [in the Western Cape] we do a better job of educating the mothers and also the nursing staff. We are equipped to serve the patients better. I think patients react to the last and loudest thing they heard. If the last thing patients heard was that nevirapine is toxic, the patients will believe it. Misinformation goes a long way (MB).

Paschke reiterates the danger of the media using the government as a source when covering nevirapine:

I think the government is sending out the wrong signals and it does filter through to communities, it does reach them and I think it has tragic effects. Stigmatisation is still a problem in communities and the

government is like a role model: they should be leaders in that regard instead of allowing it to become a political game. People want role models and they find that in the media (IP).

According to Paschke “the AIDS epidemic has lifted the lid on the patriarchal system in our country”. There is, however, still huge inequality between ordinary men and women which continues to render women more vulnerable:

It is a very foreign idea for a woman in this society to decide for herself that she wants to get pregnant; quite often women tell me, ‘no I didn’t want any more children but what can I do, he wants a child’. Maybe 25 percent who are pregnant are pregnant because they want to be (IP);

Rape in a marriage is very common, although it is not perceived as rape because of the chauvinistic background. Plain outright rape outside marriage is also common (IP).

Furthermore, once these women have been forced into sex, perhaps contracted HIV and are now unwillingly pregnant, they are often sadly, once again due to social inequality, unaware of the beneficial drug out there which can save their unborn child’s life. When asked if women were aware of the risks involved in taking nevirapine or its benefits Paschke answered that they were largely uninformed but that she:

would prefer them to be: if they are critical it would point to somebody taking responsibility for their health. The women we see are often very unempowered and are not used to making decisions due to the chauvinistic background they come from (IP).

Instead these women are open to incorrect and life-threatening information:

I think very few women know about nevirapine. This is dangerous because then they are easily misled by quacks selling dietary supplements (IP).

Besser offers some insight as to why the public are under-informed about the life-saving qualities of nevirapine and often fall into the trap of resorting to vitamins rather than ARVs. In his opinion it has a lot to do with the media's incorrect use of source which results in political agenda setting:

I think we hear a great deal about the problems that are being driven by national government: misunderstandings and their own agenda. I think that when TAC comes back with a defence of the drug it's not as good news....Rath is doing far more promotion of his views than the medical community. It should not be like this. People shouldn't hear from the denialists louder than they hear from the supporters (MB).

In Besser's opinion the medical community needs to speak out more and journalists need to seek these science sources out more actively:

I think the medical community could make more noise, I think the Provincial Department of Health needs to make more noise in response to the messages that are coming from the National Department of Health (MB).

Scientific sentiment is that in an educationally and culturally challenged country, like South Africa, "we need to take every opportunity we have [to educate]" (MB) and not voice the opinions of dissidents without also giving space to a far louder scientific voice:

If there is ambiguity in terms of health messages, people who are unclear will be confused. People will not take medicine if they are told that they don't have to or if they are convinced by campaigners that they don't have to. I know that this out there, I know that this is not urban legend (MB).

Besser's concern over the negative consequences of the media's portrayal of mixed messages and ambiguity about ARVs is echoed in the following excerpt of a signed statement sent to the Western Cape Health Minister Pierre Uys from 199 health professionals demanding a ban on AIDS dissident Matthias Rath's Rath Foundation:

Many of us [medical doctors] have had experiences with HIV-infected patients who have had their health compromised by stopping their antiretrovirals due to the activities of this [Rath] Foundation (Health-e, 2005).

According to Besser the AP December 2004 reports are a classic example of how ambiguity is sown in the minds of the public through media misrepresentation of facts around nevirapine:

There was an enormous amount of misrepresentation, based on reports coming out of the US. People tend to hear and remember the bad things: as the issue became sorted out and the issues became clearer, I'm not sure how much of *that* would penetrate public minds (MB).

It is for reasons such as these that medical experts on AIDS feel that the media need to review their policy around health reporting:

I think the media has to decide whether they are going to promote health behaviours or promote news. News is Manto standing up and saying 'garlic and potatoes', health behaviour is 'ARVs are good and life-saving'. Should the media have a view, a perspective, should it in some respects be editorial on it? I think so. I think they are a public service (MB).

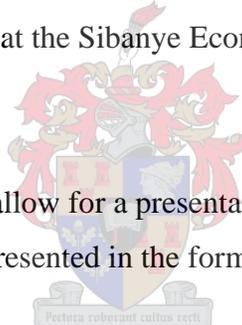
The media, according to the doctors, can play a highly positive role in addressing the correct sources and issues around AIDS in a responsible way:

As soon as people disclose their HIV status, as soon as they speak openly about their disease, they do so much better clinically. It's amazing. As soon as they put trust in somebody else it develops a relationship which blooms. The same goes for the community: as soon as the community can trust the government, as soon as they feel they can be open by following a government role model of openness, things will improve: I think you can draw the parallel there (IP).

6.2 DISCUSSION OF THE PUBLIC'S PERCEPTIONS OF NEVIRAPINE REPORTAGE

Eleven HIV positive women who had given birth with and without nevirapine were interviewed through a focus group at the Sibanye Economic Empowerment Training Centre in Khayelitsha.

The use of an interpreter does not allow for a presentation of verbatim quotes. The women's perceptions are instead presented in the form of indirect speech.



Firstly and most importantly these women were unanimous in their belief that what they receive in the media is a true reflection of reality. They also said that they rely on all three traditional news mediums, television, radio and newspapers, as a source of information on HIV/AIDS. With regard to newspapers, however, they relied mostly on community papers as they could not afford the commercial dailies.

Friends and support groups also acted as important sources of information.

All the women present were not well-informed about nevirapine before presenting at the clinic for their respective maternity check ups. Further to this the clinic did not provide them with needed information but merely instructed them to take the drugs.

One woman stated that she had, in fact, been very nervous about taking the drug after she watched a television programme which emphasised the dangers of combination therapy nevirapine such as liver failure.

This fear was later abated at an NGO support group which is where all the women say they get most of the information they require on nevirapine.

The women were not aware of the risk of resistance involved in the use of single dose nevirapine. This was evident in their strong and unanimous desire to use the monotherapy instead of the more complicated and potentially toxic combined regimen. Only one woman said she was happy with the combined therapy.

All the women expressed a strong desire to hear more positive stories about HIV positive women in the media, especially in the newspapers.

6.3 CONCLUDING INTERPRETATIONS

Both medical specialists believe that the media moulds the public's perception of nevirapine and that health reporters must practice their social obligation to their audiences with integrity by using the right sources, communicating the correct information, and setting positive educational agendas. This sense of integrity is all the more important in the light of the fact that the women at the focus group study confirmed that they do depend on media as a source of information on HIV/AIDS.

The dissemination of correct educational facts is the only way to empower these severely culturally challenged women and in so doing enable them to make an informed decision to use nevirapine in PMTCT.

That the media is not doing this adequately is seen in:

- the doctors' observation of the lack of knowledge on the risks and benefits of nevirapine in their HIV positive pregnant patients
- The fear instilled in various patients who either refuse to take nevirapine or are very nervous about taking it
- An apparent lack of awareness amongst the majority of the participants in the focus group study about the risk of resistance involved in taking single dose nevirapine: this is evident in their expressed desire to use the single dose regimen rather than the more complicated regimen of combined therapy
- Most of the women at the focus group study said they get the information they need from their support groups.

In order to attain a higher standard of integrity in health reporting on HIV/AIDS issues, the medical experts believe the media needs to re-address its media policy. When reporting on health the media must promote the pure science issues and not news as defined by commercial news values which, in the nevirapine context, leans significantly towards the political.

The science perspective demands a far stronger voicing of medical community opinion as well as a healthy use of the right role models such as women who have broken the stigma barrier and given their AIDS treatment success stories to the media. Not only does the depiction of patients as survivors break down the stigma, but it also indirectly encourages a better response to treatment, a compelling incentive indeed for health reporters to get these stories out there: especially in the newspapers which allow receivers to cut out and keep these motivating personal accounts.

The media spreads messages: misinformation goes a long way but then so, too, can the right information.

CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS

This concluding chapter summarises the main findings of the research. The overall negative and positive results are discussed as a whole and related to the literature and theory pertaining to this study.

Any ambiguities in the data are brought to the fore and suggestions are made to explore and address these issues via further research.

Finally the findings are discussed within the context of their possible implementation and what implications they may have for current media policy.

7.1 A SUMMARY AND DISCUSSION OF THE MAIN FINDINGS

In this section the most salient results from the previous three chapters are drawn together and presented within the context of those meta issues or environmental factors which influence the press's portrayal of nevirapine.

The content analysis of the texts under study reveals that nevirapine reportage during the selected time frame was slightly more positive than negative. The neutral content, however, disallowed an above 50 percent positive outcome.

Further to this the reporting was erratic and clustered around controversial events.

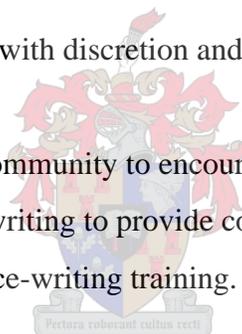
The journalistic use of mainly government sources resulted in a high political agenda and an extremely low educational agenda. The negative direction of the reports correlated to the use of government, TAC and AIDS dissident sources. These sources were often not balanced by a scientific source. Very few ordinary citizens were used as sources in nevirapine reportage and amongst these only one woman was given voice by the press to tell her AIDS story.

The above trends in the reports suggest an overall ambiguous media portrayal of nevirapine. This sense of ambiguity led the researcher to conclude, at this stage, that the media practitioners involved do not have a strong social commitment to those women living with HIV/AIDS in a patriarchal society and that the public would have a political and negative perception of nevirapine and not a clinically informed one.

Further research revealed, however, that the majority of health writers interviewed had an extremely strong desire to perform an educational and clinically informative role in getting the right treatment information to those who need it.

Their sense of integrity and social responsibility is reflected in their desire to:

- use scientific sources
- approach AIDS dissidents with discretion and caution
- set educational agendas
- rely on the voices of the community to encourage a social learning process
- incorporate more feature-writing to provide context and human interest
- benefit from general science-writing training.



The discrepancy between the negative text content and the journalists' good intentions is explained by obvious conflict these writers experience when reporting on health issues within a commercial media environment.

Here the journalists and the health and news editors interviewed indicate that the very nature of news itself, which is reactive and event-driven rather than proactive, determines the largely political and sensationalised portrayal of an already controversial drug such as nevirapine.

Within this news context journalistic social ideals about nevirapine are scuppered by commercial news values and the pressures of working on a daily newspaper whose deadlines must be honoured and whose financial demands impose under-resourcing and a

subsequent lack of health writers specialising purely in AIDS issues. As a result the quality of pure science reporting is inevitably compromised through controversy, elitist and single sourcing and faulty scientific facts.

The social awareness of the journalists and the news editor and the science and health editor, indicates that, up to a certain level within the hierarchy of a daily newspaper, there is a strong potential commitment to addressing AIDS issues in a more appropriate way.

The sense of conflict and frustration of these media practitioners, however, is not fully shared by the one managing editor interviewed. Whitfield, in his capacity as editor of an internationally owned commercial newspaper, promotes a sophisticated democratic media policy which adopts a watchdog role. While this democratic policy is admirable in its principle of allowing all voices to be heard and debated over a period of time and in its principle of playing a surveillance role on the leaders of the country to encourage justice and a healthy administration, it sets a highly political agenda which marginalises the impoverished and culturally challenged members of society who need clear and accurate scientific information on how to protect their children from a deadly epidemic.

The problem with a media policy, such as that outlined above, is that it does not take into consideration the fact that the larger and more uneducated population groups are not able to distinguish between fact and fiction. Thus the democratically voiced opinion of the AIDS dissident who promotes vitamins above and beyond ARVs, or the government who overplays the risk of drug resistance may, sadly, be taken seriously.

Such a policy demonstrates a lack of social awareness in a fledgling democracy such as South Africa where many people, previously deprived of an adequate school science education during the apartheid regime, are living with HIV/AIDS and so depend on the media as a source of health information.

This lack of social awareness is further emphasised in Whitfield's belief that the public does not rely on the media for health treatment issues whereas, according to further research, they do.

The third and final phase of the field research focused on the public itself and explored their impressions of the role of the media and how they perceived nevirapine as it is presented to them by the press.

The fact that the AIDS experts and those HIV affected members of the public interviewed, indicate that communities depend on the media, either first hand or from friends, acquaintances and other voices, as a source of information for HIV/AIDS renders the findings of this study highly relevant.

Once this media dependency had been established further exploration indicated that a scientific opinion on media performance in nevirapine reportage is highly flawed. The main issues raised against the media include:

- a heavy political perspective on nevirapine
- an inadequate use of the medical community as sources
- an overall lukewarm portrayal of nevirapine which communicates ambiguity and may instil insecurity in the media audience and render them more vulnerable to the published views of AIDS dissidents
- a missed opportunity to set educational agendas which can result in those infected with HIV refusing to take nevirapine or being totally unaware altogether of the drug
- a lack of positive role models in nevirapine reports.

The media's inability to communicate treatment information, health benefits and risks (in a responsible manner) on nevirapine is seen in the very final stage of the field research where information gleaned from HIV positive mothers at the Kayelitsha focus group indicate that:

- those affected by AIDS look to the media for knowledge but find it rather at their support groups where they feel adequately informed to take nevirapine comfortably
- unbalanced information from the media can instil unnecessary fear in those considering taking nevirapine due to irresponsible reporting on toxicity
- a general unawareness of the possibility of resistance as reflected in the participants' desire to receive sdNVP rather than the more complicated combination therapy.

7.2 AN INTERPRETATION OF THE RESEARCH FINDINGS IN TERMS OF LITERATURE AND THEORY

The analysis of the results from the field research permitted the emergence of trends and relationships between the collected data. These discovered trends and relationships appear largely to support the researcher's main initial study expectations, namely:

- Nevirapine press reportage in the Western Cape has a high negative content
- Science communication on nevirapine is side-lined by political agenda setting and commercial news values
- There is an element of inaccurate scientific facts in nevirapine reports
- The media does not "see" those infected and affected by HIV/AIDS and their reporting on nevirapine subsequently does not cater to these members of the public
- The AIDS affected community, especially women, remain un-informed and un-empowered by the media's portrayal of nevirapine.

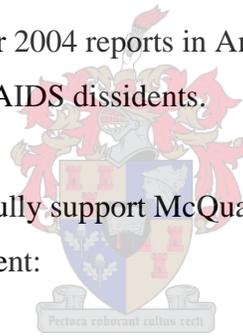
This interpretation of the data is now related to literature presented in Chapter 2 to verify published and existing theories set out in the literature review which provided the initial framework for this study.

The content analysis of nevirapine reportage over the selected time period revealed erratic or clustered reporting with a fairly high level of negative direction: results which must be considered within the context of commercial news reporting as practised by the three dailies under study.

This commercial news environment dictates journalistic allegiance to commercial news values which “tend to favour events that are about elite people, elite nations and negative happenings” (McQuail, 2000: 341).

The content analysis did in fact support this theory as seen in the representation of elitist (government) perspectives on the drug, the coverage of controversial or negative aspects of nevirapine such as the resistance issue as battled out between TAC and the South African minister of health in Bangkok at The 2004 International AIDS Conference, the controversy over the AP December 2004 reports in America on the HIVNET 012 trial and arguments between TAC and AIDS dissidents.

The erratic reports on nevirapine fully support McQuail’s theory as outlined in the literature review in that the key event:



refers to the kind of event that becomes a big news story not only because of scale, unexpectedness and dramatic quality, but because of some unusual degree of public resonance and significance in symbolising some deeper public crisis or anxiety (McQuail, 2000: 342).

Results indicate that, because of allegiance to commercial news values, health reporting on nevirapine in South Africa depends very much on the wrong sources, for example the government, TAC and AIDS dissidents. Sources with good “sales value” are quoted in line with hot selling negativity or what prominent public figures have to say:

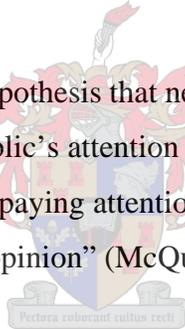
Some sources are also more powerful than others or they have more bargaining power because of their status, market dominance or intrinsic

market value....news is often reports of what prominent people say about events rather than reports of the events themselves (Oosthuizen, 2001: 205).

The high prevalence of activist and government sources, which have urgent political agendas to promote, used in nevirapine reportage furthermore back the theory that “The news is usually... weighted towards sources which are eager to provide information” (Oosthuizen, 2001: 204).

This, in combination with the fact that reporters must meet deadlines, leaves little room for satisfactory scientific balance from the voices of the medical community as reflected in the views of the AIDS experts interviewed and the lack of satisfactory clinical knowledge gleaned from the media by those living with AIDS.

These fresh findings reinforce the hypothesis that newspapers, as a part of the mass media thus “select and call to the public’s attention both ideas and events” (De Beer, 2002: 20) and “simply by the fact of paying attention to some issues and neglecting others will have an effect on public opinion” (McQuail & Windhal, 1981: 62).



It is through their selection of sources, whether it is a conscious selection or not, that reporters “gatekeep” by presenting a more political rather than scientific or educational perspective on nevirapine. The outcome is therefore a paucity of educational agenda setting in a country which cries out for education at every possible opportunity. The results from this study emphasise the importance of the suggestion that:

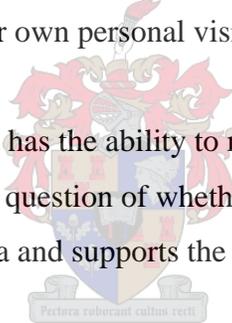
The status of the HIV/AIDS debate should be considered against the theoretical framework provided by the agenda setting hypothesis, the role of the media – in this case the print media – in a developing country such as South Africa (De Wet, 2004: 102).

The agenda setting hypothesis is so important in South Africa because the majority of her people are previously disadvantaged; especially from an educational point of view and so rely on the media, a public service, for health information amidst a raging AIDS epidemic. This substantiates the view that: “the more a society is in a state of crisis or instability, then the more power the media are likely to have (or be credited with)” (McQuail 2000: 79).

Results from the third and final stage of the field research show that the media has a direct influence on the public’s perception of nevirapine, to the extent that some refuse to take the drug. This strongly supports the hypothesis that:

We are consequently very dependent on the media for a large part of our wider ‘symbolic environment’ (the ‘pictures in our heads’), however much we may be able to shape our own personal vision (McQuail, 2000: 64).

The study findings that the media has the ability to mould the readership’s perception of a life-saving drug, answers the question of whether or not the public believe what they see, hear or read in the media and supports the outcome of previous research, namely that:



the high level of confidence registered by black respondents in the public survey (70 %) [when] the print media only caters for the interests of a small privileged minority (Hofmeyr, 2003: 13);

and:

although there is general agreement that the print media can be more balanced in its reporting, it appears as if the vast majority in all respondent groups [including Black, White, Coloured and Indian race groups across various income brackets] do not doubt its *bona fides* (Hofmeyr, 2003: 18).

The second phase of the field research explored the relationship between health reporters and their readers and the commercial media environment in which they work. This section of the research process also explored editorial opinion on the function of media policy in South Africa and how this marries with health reporting on nevirapine.

Findings disproved the researcher's expectation that reporters do not harbour a sense of social responsibility and cultural sensitivity to those, particularly women, living with AIDS.

The discrepancy between the negative content (comprising dangerous sourcing, single-sourcing, inaccurate science information and political agenda setting) and the journalists' good intentions in wanting to communicate responsibly on nevirapine finds explanation in the challenge posed to journalists reporting on health from within a news environment which imposes commercial news values and marches to the tune of a particular media policy.

Within this context journalistic awareness of and willingness to cater to a culturally challenged sector of society paralysed by a deadly disease are smothered by an editorial imposition of a first world media policy which operates from the liberal-individualist paradigm where "the role of the media is to contribute to and uphold democracy" (Fourie, 2001: 276).

Results from this study reveal that this view is presently practised by the managing editor interviewed, Chris Whitfield of *The Cape Times*, who operates from a democratic paradigm and wishes to ensure that the media plays a surveillance role:

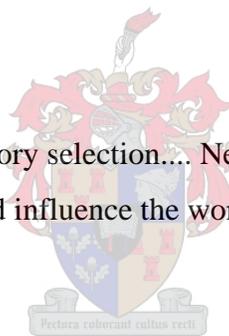
an adverse role, [the media] acts as a watchdog and agenda-setter. The media exposes violations of the moral and social order. The media informs by bringing important issues to the attention of the community. This is usually the role played by the media in developed countries and often the reason for its unpopularity with governments (Fourie, 2001: 276).

Thus, although health journalists strive to perform with integrity when reporting on health issues, their efforts are sidelined by those Western orders imposed on them by their editor which, according to the researcher, explains the negative content in the nevirapine reports despite a journalistic sensitivity to the media audience's social and cultural plight. These conclusions from this study support the theory expressed within media specialist circles:

The editor of a newspaper acts as a link between the directorate and the editorial staff (journalists). It is the editor who ultimately determines the policy of a newspaper and who has to make sure that this policy is carried out (Oosthuizen, 2001: 200);

and:

Journalists do not control story selection.... News editors and sub-editors therefore both supervise and influence the work of the journalists (Oosthuizen, 2001: 202).



It is the researcher's opinion that foreign media ownership plays a part in distancing South African media practitioners from a significant proportion of the community. An editor is answerable to those who own his newspaper and it is through the command of the editor that the media policy of the paper will have to mirror that of the international owner and it is the editor's job to ensure that that policy is practised all the way down the ranks.

Findings from this research show that there is a strong element of a lack of journalistic freedom:

the news values have become more commercially driven in the last five to six years. We are much more aware that the paper is not there so we can exercise our journalistic freedom the way we want to (EE).

It is statements such as these which support the theory that:

... Editors should thus perform their tasks in accordance with the broad guidelines laid down by their board of directors... news organisations are not democratic and the editors, and sometimes their assistants, have the power to decide what gets into print. It is therefore obvious that editors can act as strict gatekeepers and that they can discard or ignore stories or news items that do not conform to their own beliefs or policies. In this way news can be distorted. As Rothman and Lichter ... argue, editors' perceptions of the world "help filter reality for the rest of society" (Oosthuizen, 2001: 200).

The newspaper owner inevitably comes from a rich first world country, as is the case with *The Cape Times* and *The Cape Argus* which are both owned by Independent Newspapers (the Irish O'Reilly group), which can "afford" a liberal-individualist media approach because his or her fellow countrymen are educated enough to make liberal individualist choices from the democratically published array of views presented to them through the media.

This sophisticated developed world stance does not take into consideration the plight of the under-developed world of South Africa where the poor and uneducated believe everything they read and are unable to make informed decisions from the array of mixed messages presented to them via a first-world style democratic media.

This imposition of a developed world view on South Africa may not apply to such a large degree to the media policy of *Die Burger*, however, as this newspaper is locally owned by Media 24. This may explain the slightly more positive than negative content direction

of nevirapine reportage in *Die Burger* where a more socially responsible/ locally appropriate journalistic stance may be taken. This interpretation would support the hypothesis put forward by Tim du Plessis, the editor of *Rapport*:

As long as Afrikaans newspapers continue the quality of their reportage and professional presentation, they will have a market. Especially if they stay in touch with the community and anticipate its shifts timeously (Wasserman, 2005).

The overall results, however, from the content analysis, which reveal erratic nevirapine reportage with a very low educational content and a high political and informative content, and the public's obvious lack of knowledge with regard to nevirapine treatment, benefits and risks, indicate that the right messages on AIDS issues including treatment are not filtering down to those who need it. This reinforces the concern that:

The media have fallen mainly into the hands of private ownership.... Many fear that some countries (particularly those in new democracies), face new forms of colonialism, especially because of the involvement of multinational companies (Steyn, 2002: 451).

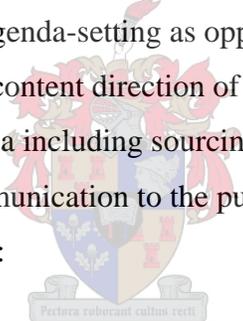
Findings from this study fully support the belief that an imposed colonial element, where the print media caters to an elite minority, marginalises a large proportion of the community who could benefit immensely from AIDS treatment education through the media. This theory holds true in the light of the comments from the editors interviewed:

One of the more justified criticisms against *Die Burger* (and perhaps other Western Cape papers, particularly perhaps the *Cape Times*) is that we ignore what may interest middle class people – we keep the marginalised communities marginalised (EE);

The only injunction I have is that *The Cape Times* is pitched at a certain readership level: “aspirational”. We aim at more or less the middle to top end of the market. There is a commercial imperative there. Are we elitist? I’m sure we could do better (CW);

I tend to think of my audience as policy makers and business people; even so if I’m writing about a drug, maybe they are interested in it for their mother or sister. We probably should think more about those consumers (A).

The researcher’s expectation that good science reporting on nevirapine, vital in South Africa – the country with the highest number of people living with AIDS, is sidelined by commercial news values and an ill-fitting media policy (both of which result in a high level of informative and political agenda-setting as opposed to educational agendas) is proved by the significant negative content direction of the nevirapine reports which are judged with regard to certain criteria including sourcing, agenda setting and the subsequent quality of science communication to the public. These results and interpretation support the view that:



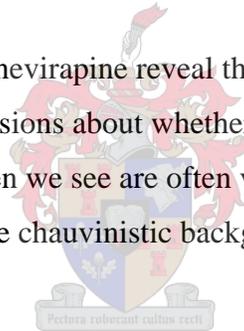
Western powers continue to set the agenda for Africa and her people
Media organisations in Africa need to urgently address the question of content and resources (Molefe, 2004: 119).

The question of content is indeed urgent within a South African gender context where the content analysis of nevirapine reportage revealed that out of the 83 reports under study only one woman’s voice from the AIDS-affected community was used to portray ARV treatment in a positive light (*The Cape Argus*, 1 December, 2004: 22). Furthermore the focus group interviews revealed that there is a strong need for women to read about how other women deal with AIDS treatment.

This low reliance on women as sources in covering the AIDS story and the public's expressed desire to read more about women who successfully live with AIDS, fully reinforces findings from recent studies where it was discovered that:

- women constitute a mere 19 percent of news sources in South Africa (GMBS, 2003: 10 - 12)
- most stories are 'gender-blind' and fail to probe the gendered dimensions of the kinds of situations that are deemed newsworthy, whether HIV/AIDS, national budgets or war (GMBS, 2003: 10 - 12)
- women are most interested in the news topics: Health and HIV/AIDS, education and social issues but
- women constitute fewer than 30 percent and just over 20 percent respectively of news sources in these topics (GMBS, 2003: 10 - 12).

Finally, results from this study on nevirapine reveal that women remain disempowered in their ability to make informed decisions about whether or not to use nevirapine as treatment for PMTCT: "The women we see are often very un-empowered and are not used to making decisions due to the chauvinistic background they come from" (IP).



This fact supports the media expert view that:

Women lack access to information they need and to which they have a right, information which would help them answer questions affecting their daily lives, problems and needs (Margaret Gallagher quoted by Strelitz & Prinsloo, 2005: 121).

The findings from this research on the media management of nevirapine reportage thus verify the theories that editors and journalists largely continue to perpetuate the disempowerment of South African women, through an under-representation of the right sources and agendas, on issues (such as nevirapine as a treatment for PMTCT) pertaining exclusively to women.

7.3 A DISCUSSION OF DEVIATIONS IN THE DATA

Most of the data collected throughout this research supports both the researcher's initial expectations and literature theory. There are, however, slight anomalies which need to be discussed.

Firstly, the study yielded an unexpected slightly higher positive (47 percent) than negative (39 percent) content direction in the studied press reports. In addition to this the researcher's hypothesis that journalists' reporting on nevirapine lacks a sense of cultural and social sensitivity towards their readership was misinterpreted as results indicate a strong sense of social responsibility amongst those reporters interviewed.

It is the researcher's opinion that these two anomalies are linked and that the higher than expected positive content direction is explained by the journalistic determination to do the best job possible within the confines of a commercially-driven news environment.

Finally, some readers of this research may feel that the target population, HIV positive mothers who live in under-privileged circumstances, are not affected by the nevirapine picture painted by the pens of reporters of daily newspapers. There may be the view that a large proportion of this stratum of society either cannot afford the commercial dailies or are illiterate and therefore "immune" to their content. Within this context the researcher, would like to draw attention to the following:

However, we cannot escape from the influence – good or bad – of mass communication. Even if we do not read newspapers or watch television news broadcasts, someone else will. Mass media information or its influence may thus not always reach us directly by means of television, the radio and newspapers, but more often than not, someone else will convey it to us. This happens because the mass media are continuously setting the agenda for trends and events as they occur on the local, national, international and even extraterrestrial levels (the scenes of

astronauts working and relaxing in outer space or the possibility of life on Mars are examples) (De Beer, 2002: 6).

7.4 THE LARGER RELEVANCE OF THE RESEARCH

Although the content direction of nevirapine reportage was discovered to be slightly more positive than negative, the drug was still not presented by the media in a consistently proactive manner. Thus results from the third and final stage of the field research show that the public is still vulnerable to misinformation due to the lukewarm and ambiguous portrayal of nevirapine as a life saving treatment.

There is therefore a wide open window of opportunity for South African media practitioners in the Western Cape to exercise their responsibility as part of a public service with far more integrity within the health reporting context. They can do this by studying the evidence provided here in this research and using it to reassess the needs of the media audience and, by doing so, work towards a more responsible portrayal of AIDS treatments.

This study focused purely on Western Cape dailies and media audiences and as such the findings can only be applied to the standard of science reporting on nevirapine in this province.

The researcher feels that a more wide-spread exploration of the public's experience of nevirapine in the Western Cape is required in order to further verify the findings from the focus groups study which played the part of a pilot study. This pilot study laid the foundation for a future survey-type approach of data collection where readers from all strata of society can be questioned on their perception of nevirapine as presented to them by the print media in the Western Cape.

Furthermore, the researcher feels it would be highly beneficial to extend this study to other provinces to ascertain the standard of science reporting on nevirapine throughout

the country. This would provide a basis for comparison and possibly offer journalists a stronger opportunity to push for necessary change in media policies.

Recommendations for an improvement in the message handling of issues pertaining to AIDS treatment from within the South African media environment are offered in the following section.

7.5 POLICY AND OTHER RECOMMENDATIONS

The analysis is complete when you feel that you can share with others what your interpretation means for policymaking, for theory, and for understanding the social and political world (Rubin & Rubin, 1995: 226-227).

At the heart of the interpretation of the findings from this research is the persistent impression that health reporting on a controversial AIDS drug simply does not marry well with the machinations of a developed world media policy which is aggressive and reactive in its role of surveillance. The dependence on negativity, elitism and political agenda setting largely robs nevirapine reportage of pure science fact and clouds the opportunity for education.

The increasingly commercial element of news values exacerbates the loss of scientific and clinical facts in reporting on a complex drug whose controversial nature has been exploited at every possible opportunity to promote political agendas and create sensationalistic content.

This developed world approach heartlessly ignores the many existing realities of the under-developed world which South Africa's new democracy must contend with. Amongst these desperate realities is the AIDS epidemic and a lack of education and an enormous gender inequality both of which fuel the spread of AIDS.

It is the researcher's suggestion that top media policy makers seriously reassess their news values system with regard to health reporting on AIDS in South Africa.

Without totally relinquishing its watchdog role the media needs to allow for a more collaborative approach to reporting within the context of all AIDS issues, especially with regard to life-saving treatments such as nevirapine.

In short, the democratic paradigm adopted by many developed world media corporations works well in a context where the public is well enough educated to distinguish between worthwhile opinions and potentially dangerous viewpoints but is at odds in a less privileged society where a lukewarm democratic presentation of many conflicting messages on a drug sows confusion and renders the more educationally challenged more vulnerable to the strong and very loud voices of authority, such as government, or the expert market trumpeting of AIDS dissidents.

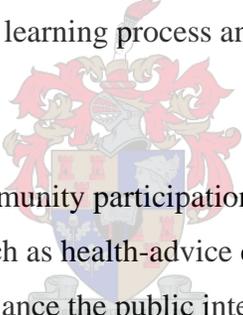
Reporting on AIDS in South Africa provides a classic opportunity for the implementation of the 'bottom-up' approach by the media which:

- 
- Voices the opinions of the public through relying on this sector as providing the socially appropriate sources
 - Humanises AIDS by giving it the faces of those who are HIV positive and who are approaching their illness as a manageable chronic condition
 - Promotes a positive and accepting public spirit
 - Encourages social learning
 - Empowers not disempowers.

This approach incorporates the attributes of development journalism (discussed earlier in this thesis) which sets socially appropriate nation-building agendas for developing countries; agendas which will promote realistic public health policies, instil power and positive attitudes through knowledge and dispel stereotypes and stigma through the representation of the voices of the people rather than of the elite authority.

It is only by listening to the ordinary voices that the media become truly aware of the real needs of their audience and the extent of their responsibility. It is only then that editors and journalists realise that there is no room for ambiguity in the portrayal of a life-saving drug in a country which has the highest number of people living with AIDS in the world. It is only then that writers and broadcasters understand the weight of their responsibility in making the uneducated and disempowered hear the voices of medical and science communities far more loudly and consistently than those voices which have only personal and selfish agendas to set.

Development journalism, which is collaborative and relies on the public as invaluable media sources, can work well in a health reporting context in South Africa because of the strong African community quality of sharing: “Africans believe in sharing, in working together, in maintaining group harmony” (Pratt *et al*, 2002; 892). This desire to share provides the ideal basis for a social learning process and a considerable potential for curbing the spread of AIDS:



Through the use of the community participation model, which involves health reporting formats such as health-advice columns and biographies, popular print media can enhance the public interest in disease prevention (Pratt *et al*, 2002; 892).

In line with developmental journalism, reporters should, when covering health issues which affect mainly women, such as the issue of nevirapine as a treatment for PMTCT of HIV, turn to the female voices within a community:

Traditionally women have played important roles in local communities. When utilised positively, women could still contribute towards ‘deploying the wealth of knowledge and skills they have gained from an insider understanding of the needs of their communities’. This has been a vital element in the process of developing and implementing media-related education and information programmes (Steyn, 2002: 459).

In addition to making room for a more developmental approach to AIDS issues (as opposed to liberal-individualistic democratic approach), media policy in the South African newsroom needs to introduce some sort of compulsory and ongoing science-writing training for its health reporters. This is because of:

- The highly complex nature of science-writing which requires journalists to translate complicated medical issues into a layperson's language
- the lack of scientists entering into journalism in this country
- the lack of a science desk in the newsroom
- the lack of health writers specialising in just AIDS issues
- the pressure of daily deadlines
- the enormity of the AIDS epidemic in the country
- the lack of a satisfactory education level inherent in those most affected by AIDS
- the pressure of gender inequality within the patriarchal social system.

Writing style, too, can play a significant role in improving AIDS reporting. Too much of a focus on the bald presentation of statistics, how HIV is transmitted and symptoms, is informative but also depressing and bland.

Instead media policy needs to allow for more in-depth feature writing which puts a face to a story which is then delicately interwoven with the science and the statistics. The facts are then rendered more interesting and memorable and the reporter has ample opportunity to provide an analytical aspect as well as the context so often lacking in the reports reviewed in this research and which would not permit politicians any opportunity for political spin.

With Africa's rich tradition of story-telling there is also scope for the introduction of narrative health reporting which literally "speaks" to the media audience. This style of writing can also provide the vital analytical and contextual elements so necessary in reporting on AIDS issues in South Africa where the topic has been subjected to extensive

political mileage. (An example of superb narrative reporting on AIDS is attached in Appendix P).

An editorial concern over the sales value of a more collaborative and developmental approach to health news is understandable as a daily newspaper is a commercial product which must be sold. The researcher feels, however, that a newspaper's largely watchdog role, which strives to promote democracy, and the more commercial news value aspect of the newspaper are permissible if media policy at least allows for a shift in reporting policy on AIDS issues and other health issues to a more socially responsible paradigm.

Perhaps media owners and editors can take comfort in the fact that international paper, Britain's *The Daily Mail*, has accomplished this successfully. It would appear, furthermore, that the South African media audience is ready for a change of diet and demands less violence and more positive educational agendas:

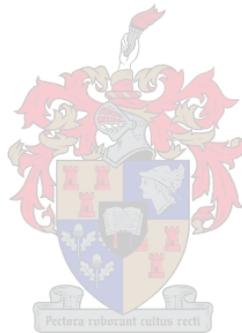
- the majority of South African women and men would find the news more interesting if the ideas and views of women were reported more often (Rama & Lowe Morna, 2005:84)
- women see education, stories about women's lives and social issues as their most important news topics (Rama & Lowe Morna, 2005: 79)
- education and social issues are amongst the top three preferred news topics for men (Rama & Lowe Morna, 2005: 79).

There is thus both a need and a financially viable opportunity to slowly introduce a shift in news policy to a more developmental approach.

The researcher strongly feels that if such an approach is adopted the media will be acting with integrity in instilling the public with a sense of dignity. Integrity and social responsibility set positive and educational agendas which can only have a beneficial outcome for the community.

Media policy makers in South Africa need to wield their power with more awareness and sensitivity because:

The media has arguably one of the deciding roles to fulfil in Africa's re-awakening. It is the modern drum of Africa, connecting villages and communities, cities and countries, through both traditional media (print, radio and television) and modern communication technologies....The media should inform, not disinform. Connect, not divide. Empower, not disempower. And: be a catalyst for development according to Africa's needs, not the West's (Rabe, 2004:3).



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APPENDIX A

NIH was warned in '02 on AIDS drug for Africa

By John Solomon, Associated Press | December 14, 2004

WASHINGTON -- Weeks before President Bush announced a plan to protect African babies from AIDS, top US health officials were warned that research in Uganda on the key drug was flawed and may have underreported severe reactions, including deaths, government documents show.

The 2002 warnings about the drug, nevirapine, were serious enough that the National Institutes of Health suspended testing for more than a year, let Uganda's government know of the dangers, and prompted the drug's maker to pull its request for permission to use the medicine to protect newborns in the United States.

But the NIH, the government's premier health research agency, chose not to inform the White House as it scrambled to keep its specialists' concerns from scuttling the use of nevirapine in Africa as a less expensive solution, according to documents obtained by the Associated Press.

"Everyone recognized the enormity that this decision could have on the worldwide use of nevirapine to interrupt mother-baby transmission," the NIH's AIDS research chief, Dr. Edmund C. Tramont, reported on March 14, 2002, to his boss, Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases.

The documents show Tramont and other NIH officials dismissed the problems with the nevirapine research in Uganda as overblown and were slow to report safety concerns to the Food and Drug Administration.

NIH's nevirapine research in Uganda was so riddled with sloppy record keeping that NIH investigators couldn't be sure from patient records which mothers got the drug. Instead, they had to use blood samples to confirm doses, the documents show.

Less than a month after Bush announced a \$500 million plan to push nevirapine across Africa to slow the AIDS epidemic, the Health and Human Services Department sent a nine-page letter to Ugandan officials identifying violations of federal patient protection rules by NIH's research. Africa accounts for more than two-thirds of the world's AIDS cases, with 27 million infected.

The NIH research "may have represented a failure to minimize risk to the subjects," the Office of Human Research Protections told Ugandan authorities in the summer of 2002.

Because of the problems, NIH shut down the Uganda research for 15 months, from the spring of 2002 to the summer of 2003, to review the science and take corrective actions.

Nevertheless, NIH officials said they remain confident after re-reviewing the Uganda study and other research that nevirapine can be used safely in single doses by African mothers and children to prevent HIV transmissions during birth. But they acknowledged their Uganda research failed to meet required US standards.

As a result, NIH recently asked the National Academy of Sciences to investigate its science in the case, and has spent millions in the past two years improving its safety monitoring and record keeping. [Continued...](#)

NIH was warned in '02 on AIDS drug for Africa

December 14, 2004

Page 2 of 4 -- "I would say there are many lessons that we have learned from this review that will help us do our clinical research, both domestically and internationally, much better," said Dr. H. Clifford Lane, NIH's number two infectious disease official.

Senator Charles E. Grassley, the Finance Committee chairman and an Iowa Republican, has asked the Justice Department to investigate NIH's conduct. In a letter released yesterday, Grassley said he was compelled to do so by "the serious nature of these allegations and the grave implications if the allegations have merit."

One lesson already derived from a closer review of the Uganda research is that even single doses of nevirapine can create instant resistance, meaning patients may not be able to use the drug or others in its class again when their AIDS worsens, Lane said.

"It was unexpected, and what it means is nevirapine probably shouldn't be a drug of first choice if other options are available," Lane said.

Lane said NIH officials were aware in spring 2002 about the impending White House announcement on nevirapine but did not tell presidential aides of the problems because they were confident, even before reviewing the Uganda research, that the underlying science was solid.

The White House also remains confident in Bush's \$500 million plan in 2002 to send nevirapine to Africa. Bush approved \$2.9 billion for global AIDS fighting next year.

"The president's mission is to try to stop the spread of AIDS in Africa and to come at it from a new angle, and that is what this is all about," spokesman Trent Duffy said.

Nevirapine is an antiretroviral drug marketed in the United States as Viramune that has been used since the 1990s to treat adult AIDS patients and is known to have potentially lethal effects like liver damage and severe rashes when taken over time.

In 1997, NIH began studying in Uganda whether it could be given safely in single doses to stop mother-to-baby transmissions. That research showed it could reduce transmission in as many as half the births.

But by early 2002, an NIH auditor, the agency's medical safety specialists, and the drug's maker all disclosed widespread problems about the US-funded research in Uganda.

Boehringer Ingelheim, the Connecticut-based company that makes nevirapine, told NIH it identified at least one "critical compliance issue" that compromised the integrity of the study and more than four dozen issues it described as "serious" and "major."

Boehringer and NIH auditors cited concerns such as failing to get patients' consent about changes in the experiment, administering wrong doses, and delays and underreporting of "fatal and life threatening" problems.

"It appeared likely, in fact, that many adverse events and perhaps a significant number of serious adverse events for both mother and infant may not have been collected or reported in a timely manner," Westat Corp. reported in March 2002. Westat is a professional medical auditing firm hired by NIH to visit and audit the Uganda site. [Continued...](#)

Page 3 of 4 -- Westat reported that there were 14 deaths not reported in the study database as of early 2002 and that the top two researchers in Uganda acknowledged "thousands" of bad reactions that weren't disclosed.

NIH said that the subsequent review whittled that list down significantly, that all deaths were eventually recorded, and that the majority of bad reactions are believed to have been caused by the poor health of patients, not the single dose of nevirapine. But they conceded it was incumbent on a US research project to disclose them fully and quickly.

Officials said the problems began when NIH converted the research from determining the drug's usefulness to supporting FDA approval for the drug. Paperwork in Uganda wasn't kept to the FDA standards, they said.

"We may not have reported exhaustively, but we reported all serious side effects," said professor Francis Mmiro, a lead doctor in the Uganda study. "What you may call a serious side effect in the US is not a serious side effect in Kampala."

NIH officials reviewed the bad news in early March 2002.

Meeting minutes, written in shorthand, raised broad concerns: Half the babies in the study were also enrolled in a vitamin A study that could have affected the outcome, and medical staff running the trials didn't follow procedures for divulging serious adverse events. or SAEs.

"No mtg minutes, no training doc[umentation], site used their own criteria for grading SAEs. No lab normal values & serious underreporting of SAEs," the minutes stated.

The minutes quote an NIH official who visited Uganda as saying, "The site staff doesn't know what they don't know."

But Tramont, the AIDS research chief, and other top NIH officials repeatedly dismissed the concerns as preliminary or overblown, and sought to salvage the flawed research's underlying conclusions rather than start over.

"There is presently no evidence that the study's scientific results are invalid," said a report Tramont sent to his staff less than two weeks after getting the March 2002 Westat audit.

In January 2002, Boehringer sent NIH an early copy of its report. But the drug maker, fearing publicity about the report might destroy its chance to get FDA approval of the drug for domestic use, asked NIH to destroy it before FDA regulators could learn about it.

"Sensitive information. Asked for it to be destroyed when audit is upon us," NIH official Mary Anne Luzar wrote on the cover page of Boehringer's report.

Boehringer says it never requested the document be destroyed, saying "our actions throughout the study evaluation were proactive and forthcoming."

Lane said the request to destroy the report was inappropriate and NIH never complied. But he conceded his agency inappropriately kept the audit from FDA for weeks, saying, "It shouldn't have happened that way." [Continued...](#)

Page 4 of 4 -- NIH at first sought to postpone the FDA review of nevirapine, then top NIH and FDA officials arranged for the drug maker to pull its US application rather than risk a public rejection that might scare African countries looking for US guidance on the drug.

Unaware of the internal NIH concerns, Bush announced in June 2002 a \$500 million effort to fight the spread of AIDS in Africa and the Caribbean. The plan's centerpiece was nevirapine.

The White House hoped the initiative would reach up to 1 million women a year and cut mother-to-child transmission of HIV by up to 40 percent.

Two years later, after hundreds of thousands of doses of nevirapine have been distributed to African mothers and children, the FDA has recommended NIH stop using the drug with certain patients.

It also has demanded stronger warnings to doctors and patients about possible lethal liver damage and rashes in patients who take nevirapine for longer periods of time.

African health officials are having second thoughts. South African officials in July recommended ending the single-use treatment because of the new concerns about drug resistance.

African doctors said they weren't aware of the full extent of NIH's concerns but feel comfortable administering it in single doses to AIDS-sickened mothers who have few other choices to protect newborns.

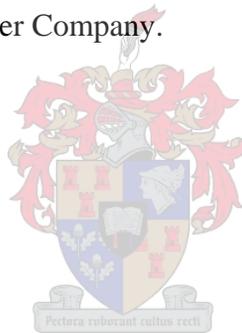
"It's not ideal, but it works," said Dr. Ashraf Coovadia of Coronation Mother and Child Hospital in Johannesburg.

Boehringer Ingelheim said it has donated enough doses to treat more than 411,000 mothers and infants in Africa and self-disclosed the problems it found with the Uganda research. But it says it has research from other locations, like Thailand and South Africa, showing single-dose usage at birth is safe and effective.

"The bottom line is there were these procedural issues, such as the speed of reporting adverse events, and the like. But the important scientific data was intact and found to be valid," said Dr. Patrick Robinson, a top Boehringer AIDS specialist.

Still, the German-owned company no longer is seeking FDA permission to use nevirapine for protecting US infants because better treatments have emerged, he said. ■

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APPENDIX B

AIDS chief says he rewrote safety report

Drug's readiness had been doubted

By John Solomon, Associated Press | December 15, 2004

WASHINGTON -- The government's chief of AIDS research rewrote a safety report on a US-funded drug study to change its conclusions and delete negative information. Later, he ordered the research resumed over the objections of his staff, documents show.

Dr. Edmund Tramont, chief of the National Institutes of Health's AIDS Division, took responsibility for both decisions. He cited his four decades of medical experience and argued that Africans in the midst of an AIDS crisis deserved some leniency in meeting US safety standards, according to interviews and documents obtained by the Associated Press.

Tramont's staff, including his top deputy, had urged more scrutiny of the Uganda research site to ensure it overcame record-keeping problems, violations of federal patient safety safeguards, and other issues that forced a 15-month halt to the research into using nevirapine to prevent African babies from getting AIDS from their mothers.

The AP reported Monday that the NIH knew about the problems in early 2002 but did not tell the White House before President Bush launched a plan that summer to spread nevirapine throughout Africa.

Now, officials have new concerns the drug may cause long-term resistance in patients who received it, foreclosing future treatment options.

"I am not convinced that the site is indeed prepared to become active," Dr. Jonathan Fishbein, a specialist the NIH hired to improve the agency's research practices, wrote Tramont in July 2003.

Fishbein contended he should be given time to review Uganda's capabilities and safety monitoring before letting the site reopen, or the NIH would risk being "toothless" in its new efforts to clean up sloppy research practices. He added that professional safety monitors hired by the NIH had reservations about the site.

Tramont dismissed the safety monitors' concerns, saying he didn't believe they fully understood AIDS.

"I want this restriction lifted ASAP because this site is now the best in Africa run by black Africans, and everyone has worked so hard to get it right as evidenced by the fact that their lab is now certified," Tramont wrote July 8, 2003, in response to Fishbein.

NIH officials acknowledge Tramont rewrote the report and overruled his staff on the reopening, but said he did so because he was more experienced and had an "honest difference of opinion" with his safety specialists. They noted he had no financial interest in nevirapine and that the troubled study began well before he joined NIH in 2001.

Those who raised objections "were part of a large team of which Dr. Tramont was the head, and it is important that the people involved in that team should express their opinion and there should be discussion," said Dr. H. Clifford Lane, the NIH's No. 2 infectious disease specialist and one of Tramont's bosses. [Continued...](#)

December 15, 2004

Page 2 of 2 --Lane said an internal NIH review concluded Tramont had not engaged in scientific misconduct. Separately, the National Academy of Sciences continues to investigate whether the Uganda research was valid.

NIH believes it helped save hundreds of thousands of African babies by allowing nevirapine to be used in single doses to block the AIDS virus, Lane said. But he acknowledged the research was imperfect, and NIH now believes nevirapine should no longer be a first choice for newborn protection if other options exist because of the newly discovered problems about resistance.

Tramont wrote in 2003 e-mails that he reopened the clinics because he didn't want NIH "perceived as bureaucratic but rather thoughtful and reasonable" and that it was important to encourage Africans' fight against AIDS "especially when the president is about to visit them."

Bush visited the continent a few days after Tramont ordered the clinics reopened.

Tramont's actions, however, drew a blunt reply from his top deputy.

"I think we are cutting off our noses to spite our face here," wrote Jonathan Kagan, the AIDS Division deputy director. "We should not be motivated by political gains, and it's dangerous for you, of all people, to be diminishing the value of our monitors."

Tramont prevailed and the research resumed. A few days later, Tramont sent a note to his staff ordering the end of an 18-month-long debate inside the NIH over whether the science from the Uganda trials was valid and safe. That debate began in early 20002 when two audits divulged widespread problems with the research.

The Uganda trial "has been reviewed, remonitored, debated, and scrutinized. To do any more would be beyond reason. It is time to put it behind us and move on," Tramont wrote in a July 13, 2003, e-mail instructing his staff that future issues about the drug be handled directly by his office.

Five months earlier, Tramont surprised one of his own medical officers who had written a report summarizing safety concerns uncovered during a second review of the Uganda trial.

Dr. Betsy Smith's report, finished in January 2003, said that the Uganda trial suffered from "incomplete or inadequate safety reporting" and that records on patients were "of poor quality and below expected standards of clinical research."

She strongly urged the NIH not to make sweeping conclusions about nevirapine based on the Uganda research. "Safety conclusions from this trial should be very conservative," she wrote.

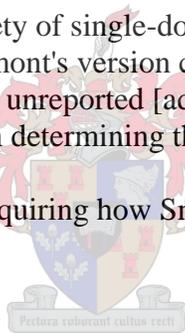
Behind the scenes, Tramont asked to see Smith's report before it was submitted to medical authorities, including the Food and Drug Administration. "I need to see the primary data -- too much riding on this report," Tramont wrote Jan. 23, 2003.

A few weeks later, the safety report was published and sent to the FDA without Smith's concerns and with a new conclusion.

The study "has demonstrated the safety of single-dose nevirapine for the prevention of maternal to child transmission," Tramont's version concluded. "Although discrepancies were found in the database and some unreported [adverse reactions] were discovered . . . these were not clinically important in determining the safety profile."

In disbelief, Tramont's staff began inquiring how Smith's report got changed. An answer came back from the top.

"I wrote it," Tramont responded. ■



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APPENDIX C

“AP Exclusive: Woman Died During AIDS Study”

Associated Press (12.16.04)::John Solomon; Randy Herschaft

Joyce Ann Hafford — who was 33, pregnant, and HIV-positive — enrolled in a federally funded research project in hopes of preventing her newborn from becoming infected. She died last year after doctors continued to administer an experimental drug regimen despite signs of liver failure, government memos say. Family members said they were never told the National Institutes of Health had concluded that the therapy likely caused her death; they learned this from documents recently obtained by the Associated Press.

In July 2003, the Tennessee woman was hospitalized and on a respirator, and top government scientists were monitoring reports of her worsening condition. NIH officials suspected the drug regimen was the cause as it contained nevirapine. Since at least 2000, the government has warned that nevirapine could cause lethal liver damage or rashes when taken in multiple doses over time.

“Ouch! Not much [we] can do about [dumb] docs,” Dr. Edmund Tramont, chief of NIH's AIDS Division, wrote in an e-mail after his staff reported that physicians continued giving Hafford nevirapine and Combivir despite signs of liver failure.

NIH officials acknowledge that experimental drugs — probably nevirapine — caused Hafford's death, and that keeping this information from her family was inappropriate, but said they usually leave such disclosures to the treating physicians. Results of the study in which Hafford was enrolled led researchers to conclude that “continuous nevirapine may be associated with increased toxicity among HIV-1 infected pregnant women” with certain liver cell counts.

Dr. H. Clifford Lane, the second-ranking infectious-disease specialist at NIH, said Hafford should have signed an NIH-approved consent form at the outset. The warning about the possibility of liver failure appears on the sixth page of the 15-page document, which is filled with complex medical terminology.

Hafford's infant, Sterling, was delivered prematurely by Caesarean section. Hafford died less than 72 hours later, on Aug. 1, 2003. The baby was not HIV-infected. He and Hafford's older son are being reared by Hafford's mother, Rubbie Malone.

NIH's official review said Regional Medical Center in Memphis, where Hafford died, failed to react to lab tests showing she was experiencing liver failure well before her death. Jim Kyle, attorney for the hospital, declined comment due to the family's pending litigation.

In response to Hafford's death, NIH ordered changes in the rules its researchers follow in nevirapine studies to ensure early detection of liver problems, according to memos. Dr. Jonathan Fishbein, NIH's chief of good research practices, is seeking federal whistleblower protection after raising concerns about NIH's practices.

APPENDIX D:

Excerpts From AIDS dissident Anthony Brink's online publication *The Trouble With Nevirapine*.

The full text can be found in pdf form on:
www.tig.org.za/pdf_files/trouble_nevirapine.pdf

(NB: Highlights in bold are the researcher's own to draw attention to particularly inflammatory or erroneous comments).

“A single oral dose [of NEVIRAPINE] given about six hours before delivery “readily crosses the placenta and is found in breast milk” so “mothers should discontinue nursing if they are receiving VIRAMUNE.” **So as not to expose the baby to more than it got in the womb. Because it's so poisonous.**

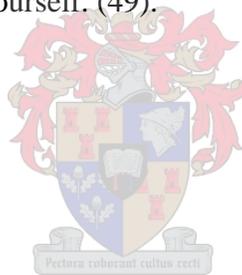
Soon after licensing in South Africa, nevirapine hit a bump in the road. Approval of the drug by the MCC presented a grand opportunity to Triangle Pharmaceuticals, an American pharmaceutical corporation founded by former GlaxoSmithKline Director of Research and AZT promotor, David Barry. Eager to cut a slice of the AIDS-drugs action, **it needed some guinea pigs on which to try out its experimental drug Coviracil** (Emtricitabine, *alias* FTC), ahead of a licence application to the FDA. Penurious South African blacks being ideal. **Being unimportant and dispensable. Not such a fuss if they get hurt or killed.** Nice and cheap too. Compared to what such test subjects cost back home in the US. Fifty rand to each for every hospital visit – about five dollars. Triangle engaged Quintiles Transnational, described at the time by a Yank newspaper, the *Raleigh News and Observer*, as “the world's largest pharmaceutical services company”, to conduct a clinical trial with Coviracil in combination with nevirapine and two other drugs, lamivudine (3TC, an AZT lookalike) and stavudine (d4T, another one). Dr Mariette Botes, an ‘AIDS expert’ at the University of Pretoria and head of the AIDS clinic at Kalafong Hospital in Pretoria, was hired to run the trial there, one of sixteen sites at which the study was conducted. Its subjects were drawn from Atteridgeville, a largely impoverished dormitory complex outside Pretoria for Sotho speakers. The study was called FTC 302. **It was an abattoir** (pp. 30-31).

‘AIDS experts’ tell us that unlike other viruses, HIV is a retrovirus that burrows into and actually becomes part of our DNA. That infected pregnant women can infect the babies they are carrying. And that, according to Guay, a single pill of nevirapine administered just before birth can prevent this. **If the mother's virus has had nine months to reach the baby through the placenta, the umbilical cord, and all those shared fluids, and thereafter ingratiate itself into the baby's DNA, would someone care to explain the value of the magic pill? How it can possibly prevent anything? Particularly since administration of nevirapine alone has no effect on CD4 cell counts, and no significant effect on ‘HIV RNA’.** Since its putative activity is reverse transcriptase inhibition, the drug is notionally only able to prevent the infection of new cells – not eradicate HIV from already infected cells, or prevent such cells from expressing new HIV

particles. So if the child is ‘infected’ by the mother while *in utero* during the nine months it is being carried, administering nevirapine as she goes into labour is completely pointless. **As is giving it to the neonate: The drug concentration in the neonate’s blood achieved by the recommended dose of 2 mg/kg following birth is much lower than the concentration determined to be necessary for an antiretroviral action, anyway.** Likewise the concentration of the drug found in breast milk, so it can’t prevent infection via breastfeeding either (pp54-55).

But Guay claimed: “Most vertical transmission occurs during active labour because of maternal blood transfusions to neonates [?!] and direct exposure to virus during passage through the birth canal [nasty place that – to ‘AIDS experts’]”, citing a couple of **speculative studies proposing that mothers infect their babies during labour and birth.** Which makes it hard to understand why in the West AZT is administered for many weeks before it. Especially since it doesn’t reduce maternal ‘viral load’. British ‘AIDS experts’ aren’t too sure about this last-minute stuff anyway. Certainly not in all cases. (55).

Don’t bother asking ‘AIDS experts’ about any of this stuff though, let alone your family doctor. They’ll huff and puff with dismissals and haughty assurances, but in truth won’t have a clue as to what you’re even talking about. (Been there, got the tee shirt.) You’ll have to read up for yourself. (49).



APPENDIX E

NEWSPAPER	DATE	AUTHOR: M/F	SOURCE/S: M/F

HEADLINE	
CONTENT	
AGENDA	

-		+	
Expressions of opposition to nevirapine		Expressions favouring nevirapine	
Actions in opposition to nevirapine		Actions in support of nevirapine	
Statements attacking proponents of nevirapine		Statements supporting proponents of nevirapine	
Statements supporting AIDS dissidents within nevirapine context		Statements against AIDS dissidents within the nevirapine context	
Misleading statements confusing/not defining sdNVP and NEVIRAPINE combination therapy as different treatments		Statements correctly/clearly portraying sdNVP and NEVIRAPINE combination therapy as different treatments	
Political statements from the opposition or activists which merely attack government and do not provide information or motivate action on nevirapine		Useful political statements from the opposition which inform/set the record straight and motivate action on nevirapine	
Nevirapine costs more of a concern than its benefits		Nevirapine cost and clinical benefits	
Misleading/inaccurate scientific statements		Clear and accurate scientific statements	

		about nevirapine. Scientific source unquoted (SSU) / Scientific source quoted (SSQ)	
Inaccurate statistical statements		Correct statistical statements	
Inaccurate clinical information statements about treatment choice/alternatives and application		Correct clinical information statements about treatment choice/alternatives and application	
Inaccurate statements on the transmission of nevirapine resistance through breastfeeding		Accurate statements on the transmission of nevirapine resistance through breastfeeding	
Statements sensationalising the risk of nevirapine resistance		Statements responsibly reporting nevirapine resistance	
Unbalanced statements portraying nevirapine as generally unsafe		Balanced statements depicting nevirapine as safe to use in the context of the AIDS epidemic	
Statements sensationalising the risk of nevirapine toxicity		Statements responsibly reporting nevirapine toxicity	
Statements giving incorrect statistical information		Statements giving correct statistical information	
Statements depicting the public in general as victims of nevirapine		Statements depicting the public in general as benefiting from nevirapine	
Statements depicting women and infants as victims of nevirapine		Statements depicting women and infants as benefiting from nevirapine	
Statements about nevirapine which		Statements about nevirapine which	

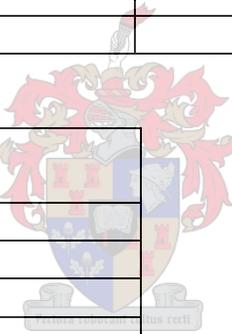
exacerbate the AIDS stigma		break down the AIDS stigma	
Stigma insensitive statements		Stigma sensitive statements	
Gender insensitive statements		Gender sensitive statements	
Culturally and socially insensitive statements		Culturally and socially sensitive statements	
Miscellaneous		Miscellaneous	

0

Other themes

Nevirapine safety status to be/is objectively reviewed			
Consequences of withdrawal/acceptance of sdNVP			
Miscellaneous			

CONTENT TOTALS	HEADLINE CONTENT
+	+
-	-
0	0
Net	Net



TOTAL NET SCORE

APPENDIX F

Questions posed to editors regarding nevirapine reportage

(The context of the study is firstly explained and the interviewee is thanked for his/her time)

- 1 How do you think the South African media should function in society?
- 2 What is your paper's media policy?
- 3 Who decides on your paper's media policy?
- 4 Which news values do you operate by? Do you think news values, when reporting on health or science, should differ from the standard commercial news values?
- 5 In your opinion, what is the primary role of a journalist in reporting on nevirapine?
- 6 Who do you recommend your journalists use as sources when reporting on nevirapine?
- 7 What is your opinion of single-dose nevirapine as a treatment for the prevention of mother-to-child transmission of the HIV virus?
- 8 In your opinion, are men or women more susceptible to contracting HIV?
- 9 In your opinion, does the gender inequality imposed on women by South Africa's largely patriarchal culture have any influence on the spread of AIDS?
- 10 How do you perceive the majority of women in South Africa?
- 11 Do you think the majority of South Africans use the media as an important source of science and health information?
- 12 Do you recommend science-writing training for your reporters?
- 13 How can science reporting on issues such as nevirapine be improved, in your opinion?
- 14 Is there anything else you would like to add that you feel I have omitted?

APPENDIX G

Questions posed to journalists regarding nevirapine reportage

(The context of the study is firstly explained and the interviewee is thanked for his/her time)

- 1 Do you think the average person believes what he/she hears, sees or reads in the media?
- 2 Do you think the majority of South Africans use the media as an important source of science and health information?
- 3 How do you perceive your function as a journalist when reporting on issues of health and science?
- 4 Do you think AIDS dissidents, like Matthias Rath, should be given voice in the media?
- 5 When you report on nevirapine what is uppermost in your mind?
- 6 Which sources do you use when reporting on nevirapine as a treatment for the prevention of the spread of AIDS?
- 7 How often would you say you use public voices when reporting on nevirapine
- 8 Of these sources how many are women?
- 9 In your opinion, are men or women more susceptible to contracting HIV?
- 10 In your opinion, does the gender inequality imposed on women by South Africa's largely patriarchal culture have any influence on the spread of the HIV virus?
- 11 How do you perceive the majority of women in South Africa?
- 12 What is your opinion of single-dose nevirapine as a treatment for the prevention of perinatal mother-to-child transmission of HIV?
- 13 In your opinion, which drug, single-dose nevirapine or combination therapy nevirapine, creates resistance?
- 14 In your opinion, which drug, single-dose nevirapine or combination therapy nevirapine, causes toxicity?
- 15 How do you understand nevirapine to operate?
- 16 When reporting on nevirapine, or any nevirapine-related issue, have you ever felt that an important health or science issue has been side-lined or framed by your editor because it does not fit in with in-house media policy?
- 17 What is your opinion of the December 2004 AP reports on the administrative issues surrounding the HIVNET 012 trial?
- 18 Have you ever done any science writing training? (In-house or on your own initiative).
- 19 In your opinion, what improvements can be made about reporting on issues such as nevirapine?
- 20 Is there anything else you would like to add?

APPENDIX H

QUESTIONS POSED TO AIDS SPECIALISTS CONCERNED WITH THE TREATMENT OF HIV POSITIVE MOTHERS

- 1 How long have you been at this treatment centre?
- 2 Why are you, as a medical specialist, involved in perinatal mother-to-child transmission of HIV?
- 3 How many mothers do you see each week on average?
- 4 Which nevirapine regimens are you currently using?
- 5 What is your personal opinion of sdNVP within a South African context?
- 6 Are any of your patients wary/afraid to use nevirapine?
- 7 Do you encounter a lot of fear of the AIDS stigma amongst your patients?
- 8 What percentage of the women you see are pregnant because: a) they want to be; b) they have been raped; c) they are unable to negotiate safe sex?
- 9 Have you any comment to make on the South African media's general portrayal of both sdNVP and combination therapy nevirapine?
- 10 Do you have any comment on the quality of science reporting in South Africa?
- 11 Where, in your opinion, do your patients get their information on nevirapine from?
- 12 If they get their information on nevirapine from the media, do you think they believe/trust what they see, hear or read?
- 13 Are any of your patients ever confused by AIDS dissident information? (for example Matthias Rath)
- 14 Do you have an opinion of the media's representation of the December 2004 administrative question marks over the Ugandan HIVNET 012 study?
- 15 Is there anything further you'd like to add?

APPENDIX I

QUESTIONS POSED TO WOMEN, AS INFORMANTS IN A FOCUS GROUP STUDY, AT THE SIBANYE COMMUNITY WORKSHOP IN KAYELITSHA FOR HIV POSITIVE MOTHERS

Thank you all for taking part in this study about the drug nevirapine. What you have to say now will help us to understand how you feel about your treatment and how much you know about it. The questions you will be asked are part of a study which we hope will help you get even more information to assure you that you are making the right decisions about the health of your children.

- 1 Do you believe that what you hear in the news is a true reflection of reality?
- 2 Do you depend on the newspapers, TV or the radio as sources of information about HIV or AIDS?
- 3 If you do not use newspapers, TV or the radio as sources of information about AIDS treatments, like nevirapine, who *do* you rely on for this information?
- 4 How do you feel about the use of single dose nevirapine as a treatment to stop the spread of HIV from mother to child?
- 5 Would you like to hear more positive stories in the news about HIV positive women who have used nevirapine successfully to prevent the spread of the virus to their babies?
- 6 Do you understand how nevirapine works as a treatment for the prevention of the spread of HIV from mother-to-child?
- 7 Do you feel that you have enough clinical information on nevirapine to make an informed decision about whether or not to use it?
- 8 Has anything you have heard about nevirapine caused you lots of anxiety?
- 9 If the answer to the above question is 'yes', can you remember where you got the information?
- 10 What do you understand about HIV resistance to nevirapine?
- 11 What do you understand about other side effects of nevirapine?
- 12 Who do you trust more about information on nevirapine, the Government or the doctors?

I have finished with my questions but is there anything else that anybody would like to add?

Thank you again for your time.

Xhosa translation:

QUESTIONS POSED TO HIV POSITIVE MOTHERS AS INFORMANTS IN A FOCUS GROUP STUDY.

Ndiyanibulela nonke ngokuthatha inxaxheba kolu phando lwechiza i-nevirapine. Eniza kukuthetha apha kuza kusinceda siqonde indlela eniziva ngayo ngonyango lwenu kwaye nazi kangakanani ngalo. Imibuzo eniza kuyibuzwa ikwayimibuzo yophando esithemba ukuba iza kuninceda ukuba nifumane ulwazi oluthe kratya ukuqinisekisa ukuba nenza izigqibo ezizizo ngempilo yabantwana benu.

1. Ingaba uyakukholelwa na okuva ezindabeni ukuba ngumfanekiso wokwenyani wento eyenzekayo?
2. Ingaba uxhomekeka kumaphephandaba, Umabonakude okanye unomathotholo njengezixhoba zolwazi mayelana neHIV okanye ugawulayo (AIDS)?
3. Ukuba awusebenzisi maphephandaba, umabonakude okanye unomathotholo njengezixhoba zolwazi mayelana nokunyangwa kukagawulayo (AIDS), ngenevirapine, uxhomekeka kubani ukuze ufumane olu lwazi?
4. Ingaba uyibona njani into yokusela kube kanye inevirapine njengonyango lokunqanda ukusasazeka kweHIV ukusuka kumama ukuya kusana?
5. Ungathanda ukuva ngakumbi amabali akhayo kwindaba angomama abanesasulela ngculaza (HIV) abakhe basebenzisa inevirapine ngempumelelo ukunqanda ukugqithisela intsholongwane kwintsana zabo?
6. Ingaba uyayiqonda indlela esebenza ngayo inevirapine njengonyango lokuthintela ukusasazeka kweHIV ukusuka kumama ukuya kusana?
7. Ucinga ukuba unolwazi olwaneleyo lwaseklinikhi ngenevirapine khon'ukuze ukwazi ukwenza isigqibo esisiso sokuba uza kuyisebenzisa na okanye hayi?
8. Ingaba nayiphi na into oyivileyo ngenevirapine ikwenze waphelwa luloyiko?
9. Ukuba impendulo kulo mbuzo ungentla ngu ewe", ungakwazi ukukhumbula ukuba wawulufumana phi ulwazi?
10. Yintoni oyiqondayo ngokungasebenzi kwenevirapine kwiHIV?
11. Yintoni oyiqondayo ngezinto ezithi zenzeke xa usebenzisa inevirapine?
12. Ngubani omthemba kakhulu ngolwazi lwenevirapine, nguRhulumente okanye ngooGqirha?

Ndigqibile ngemibuzo yam kodwa ingaba ikhona enye into enifuna ukuyongeza?

Enkosi kakhulu kwakhona ngexesha lenu.

APPENDIX J

Aids drugs fail acid test

April 6, 2004

CAPE ARGUS

Goodbye Treatment Action Campaign, hello nutritional medicine.

The TAC leadership seems to fall apart as anti-retrovirals fail the acid test in hospital wards.

The government task team report released last year spells out the fact that anti-retroviral therapy is "not without its hazards".

It says the drugs have serious side-effects and there have been instances of heart disease, cancer and abnormal cholesterol concentrations.

"There have also been cases of death as a direct result of anti-retroviral usage," the report says.

With reference to the article, "Natural product to hit market for Aids patients", which appeared in the press on March 23, I reckon South African experts such as Professor Serfontein are on the right track at the right time and right place. The scourge of Aids will be defeated sooner than expected.

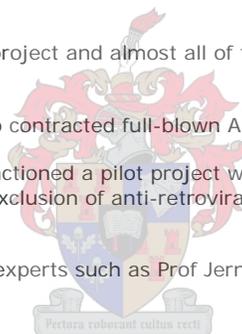
It is interesting that Professor Giraldo from the US has conducted a pilot project on the use of nutritional medicine in Mexico.

He had 800 full-blown Aids patients on the project and almost all of them regained optimal health and have returned to work.

Here in South Africa, almost all patients who contracted full-blown Aids in 2002 and were on anti-retrovirals, have died.

So wouldn't it be wise if the government sanctioned a pilot project where only nutritional medicine is administered to the exclusion of anti-retrovirals. And then compare the success rate between the two.

This idea is supported by international Aids experts such as Prof Jerndal (Brazil), Giraldo and Prof Foster (Canada). I hope the government is listening.



The TAC is in a dilemma. Mark Heywood admits the failure of nevirapine, yet he is supporting its use because there is no alternative treatment.

On the other hand, Mandla Majola insists on the effectiveness of anti-retrovirals.

The thinking behind the Treatment Action Campaign was to persuade the government to supply the toxic anti-retroviral drugs to public hospitals and clinics.

Now that the government is providing anti-retrovirals, the role of the TAC has died a natural death.

I think the TAC should maintain a dignified silence as to how doctors go about performing the duties for which they were vigorously trained. By talking too much, some individuals in our communities expose their ignorance on medicine, let alone pharmacology.

Most people are unaware that the Father of Medicine, Hippocrates, extolled the virtue of garlic because it has the following medicinal ingredients: selenium, magnesium, zinc, potassium and amino acids, and it is a chelating agent.

Compressed garlic with all its medicinal properties may cost R300 at the chemist, whereas an uncompressed garlic simply costs 10 cents at the spaza shop in Khayelitsha.

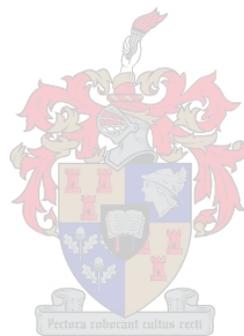
It goes without saying that Minister of Health Manto Tshabalala-Msimang is doing a sterling job by encouraging the public to use garlic as well.

Garlic is cost-effective, with no toxins, and is more accessible to the poor and

unemployed who are ill.

When all things are considered, the final judgment on the efficacy of nutritional medicine and anti-retrovirals will be handed down by the patients themselves.

Dr M Chaza
Aids Medical Specialist
Cape Town



APPENDIX K

SLUG:	aids01 main	SOURCE:	Group writers SA
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DATE:	2004-12-01 11:00:01	AUTHOR:	Kerry Cullinan
EDITION:	1	PAGE NUMBER:	22

The transformation of Deli Sindane

Despite the government's decision to make anti-retroviral drugs available free at certain public clinics and hospitals, many people are too afraid of the stigma associated with HIV/Aids to take advantage of these life-saving drugs. One woman took the plunge.

Fourteen months ago, Deli Sindane was at her lowest ebb. Shortly after the death of her four-day-old baby daughter, the 20-something Deli began to withdraw into a trance-like world of immense tiredness and ill health.

It was during her pregnancy with this, her first child, that she found out, after a routine test, that she was HIV-positive. Her long-time partner and the father of the baby was tested and learnt that he, too, was HIV-positive.

"He blamed himself for my status because he admitted he had many girlfriends," says Deli.

Their daughter was born prematurely, a common occurrence for immune-compromised women, and died after four pain-filled days.

"I called her Sinikithemba (give us hope) because I had hope for her. But still she died," Deli recalls.

After that, Deli's health deteriorated rapidly. She began to lose weight and cough up blood.

She became nauseous, feverish and had night sweats.

She was admitted to St Mary's Hospital in Mariannhill and spent a month there on TB treatment.

The hospital then referred her to its HIV/Aids treatment clinic, iThemba. By

that time her CD4 count (measure of immunity in the blood) was 71.

When I met her at iThemba, Deli wasn't sure that she wanted treatment.

"That time, I was not sure about the anti-retrovirals (ARVs)," says Deli.

"I heard rumours that the ARVs make you even sicker. So I wasn't sure about taking them."

Back then the government had not yet decided to make ARVs available in public hospitals so iThemba Clinic had raised funds for 30 people to take ARVs, and Deli was one of the potential candidates.

Initially Deli's chances of being accepted looked slim as she did not show much commitment to the six-week drug readiness course she was required to go on.

She was usually late for training sessions, hardly engaged with the other women in the class and could barely meet anyone's eye. She would often giggle rather than answer questions.

"I was so shy because I was not sure that the ARVs were working. I also thought I was going to die, so I was quiet," she admits.

"And I was scared of the other women in the class because some were coming from my township and I thought they were going to tell people that I have HIV," she recalls.

Until now Deli has been unable to tell her mother and her three younger brothers that she is HIV-positive and taking anti-retroviral drugs.

But she has decided to make a public disclosure because "there are still far too many people hiding and dying, when there is treatment available for them", she says.

The cost of this secrecy hit home recently after the death of her 29-year-old cousin, who died of an Aids-related illness.

"Just before he died he said he was sorry to his family for wasting their money on medicines because he knew from last year that he was HIV-positive.

"He would have still been alive if he had told me, or asked about anti-retroviral treatment," says Deli.

Deli's sister and brother-in-law have both died of Aids-related illnesses in the past three years.

As the weeks progressed at iThemba, trust started to grow among the 10 women on the course. They shared how they had been shunned by family and friends.

How they believed death was upon them. How they worried about who would take care of their children. That they feared others in the group would gossip about them.

Deli started to take note of what trainer Zinhle Thabete, also HIV-positive and on treatment, said about the importance of valuing her own life enough to try to save it.

She also learnt all about the drugs she might take and what possible side-effects they might bring.

By the end of the six-week training programme, Deli was ready to give the drugs a try. So she took a big step and told her sister that she was HIV-positive - one of the requirements of the programme was disclosing your HIV status to one person you live with - and she was accepted on to the programme.

Initially, she was taking the drugs 3TC and D4T at 6am and 6pm each day, and efavirenz (Stocrin) at 9pm. Efavirenz is renowned for inducing nightmares, something that Deli had been warned about during class.

"I had vivid dreams, like I was stuck in rocks in a bright place. It was scary, but I had been told to expect the nightmares so I didn't stop taking the tablets," says Deli.

A month later, the dreams had subsided. A few months later, Deli started to think about the future again and she and her boyfriend decided that they would like to have a baby in the future.

"I discussed this with the doctors and they advised me to take nevirapine instead of Stocrin because Stocrin can damage the foetus," says Deli.

The change-over from one drug to another was smooth and there were no side effects this time.

By June, after a year on treatment, Deli's CD4 count was 259 and her viral load (measure of HIV in her body) was undetectable.

Better still, Deli now had a job at one of iThemba's sister clinics counselling

the mothers of HIV-positive babies. This after she had paid to attend a counsellors' training course and volunteered at the clinic for a month.

When we meet again after many months, I am struck by the change in her.

The uneasiness and tension in her body has gone. She is calm and confident, looking me straight in the eye.

"I am okay now," she says. "I just have some stress because of my boyfriend. I discovered that he has made two other women pregnant. The one he said he wanted to give HIV to because she was rude.

"I have decided that I don't want him anymore. He is infecting others and re-infecting himself, and what about me? It is hard because we were so long in love, since 1996 and he has started to pay lobola for me.

"But I need to look after myself now."

Deli hopes that her life story will help to eradicate the stigma and silence that still envelops HIV/Aids more than a quarter of a century after the start of the global epidemic.

Even well-to-do families who can afford private treatment are affected by this silence.

Chief Mangosuthu Buthelezi, leader of the IFP, has lost two children this year to HIV/Aids.



Many people are either unaware that they are living with HIV or are reluctant to come forward for treatment.

Often people only come for treatment when their CD4 count is very low, which makes it more difficult to treat them.

Anti-retroviral therapy is recommended for those with CD4 counts of 200 and lower.

Professor Robin Wood, of UCT, uses the analogy of sinking sand, saying that the lower the person's CD4 count, the harder it is to pull them out of this life-threatening situation.

"The immune systems of all patients start to improve almost immediately on anti-retroviral treatment, but some patients with CD4 counts under 50 may initially appear to get sicker on treatment," he says.

When patients have advanced HIV disease, he explained, their immune

systems may be too weak to respond to a number of illnesses.

"The body starts shutting down. It mounts no immune response and these illnesses go undiagnosed.

"But as patients' immune systems respond to treatment and start to get stronger, they start to recognise these illnesses and fight back.

"This usually shows up as an inflammation and it may look as if these patients have developed new illnesses and are getting sicker."

Doctors call this "immune restoration syndrome" and it usually manifests in the first three months of treatment.

"The first 100 days of treatment are crucial in people with low CD4 counts.

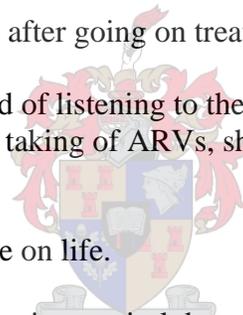
"This is when these undiagnosed illnesses usually start to appear, but their immune systems may not yet be strong enough to fight back," says Wood.

This explains why patients still die after going on treatment.

Deli Sindane took a chance. Instead of listening to the rumours and superstitions that still surround the taking of ARVs, she decided to find out for herself.

In return, she has found a new lease on life.

"Come forward and ask for help. Anti-retroviral drugs are working and helpful," she urges. - Health-e News Service



APPENDIX L

Cape Argus 1/12/04, Bruce Venter: **“Women, children increasingly vulnerable”**

DESPITE government’s roll-out this year of anti-retrovirals (ARVs) drugs to combat the HIV/Aids pandemic, women and children remain increasingly vulnerable to the disease.

One in five women are HIV-positive, yet only 1% have access to ARVs.

Women represent 58% of those living with HIV/Aids in southern Africa, with 13 becoming infected for every 10 men.

In terms of infection 13.3 million women live with the disease, compared to about 11 million men.

With more than 5 million infected South Africans, an estimated 600 people die daily from HIV/Aids-related illnesses.

Most HIV infections in children under the age of 12 occur through mother-to-child transmission or soon after birth.

The South African health review says a single dose of Nevirapine can reduce mother-to-child transmission by up to 50%.

HIV/Aids is expected to push South Africa’s infant mortality rate to almost 100 per 1 000 live births by 2010.

Michaela Clayton, of the Aids Law Unit with the Namibian Legal Assistance Centre, says gender discrimination increases women’s vulnerability to infection.

“Women and other vulnerable groups are particularly at risk of infection. Largely because of unequal status in society,” said Clayton.

This discrimination deters women from seeking HIV/Aids testing and treatment, says Clayton, in attempts to escape the stigma and discrimination associated with HIV-related illnesses.

Sisonke Msimang, of HIV/Aids action group UNAids, says little is being done to reduce women’s risk of contracting the disease.

“Sexual aggression and violence are important factors when considering the high infection rates among women,” said Msimang.

Women cannot always negotiate safe sex or alter their partner’s behaviour, says Msimang, and are therefore prone to sexual violence. “Aids is seen as a disease with a ‘woman’s face’ and, with existing gender inequalities, the HIV/Aids stigma is reinforced,” she said.

Bowing to public pressure, government announced earlier this year that it would start its ARV roll-out in selected state hospitals.

Commenting on the ARV programme, Health Minister Manto Tshabalala-Msimang said the strengthening of the health system and other HIV/Aids programmes had laid a firm foundation for the much-anticipated ARV roll-out. “Our mother-to-child prevention initiative and voluntary testing and counselling programmes have assisted us in successfully implementing the ARV roll-out,” she said.

Clayton warned, however, that prevention programmes were underscored by failures in changing public perceptions and addressing social inequalities.

“Social inequalities determine both the distribution of HIV as well as the health outcomes of those affected.”

APPENDIX M

EDITORS

Three editors were interviewed: The editor of *The Cape Times*, Chris Whitfield; the news editor at *Die Burger*, Estelle Ellis and the science and health editor of a national daily who requested to remain anonymous.

The categories below were defined by both the researcher's original questions and additional issues that arose during the interviewing process. Comments are recorded with the initials of the relevant participant: statements from the anonymous participant are denoted by the letter "A".

Categories:

Function of the media

In any society a media's fundamental role is a watchdog one. In our society it is complicated a lot by two factors:

- a) Change to a new democracy, new people coming in who are unfamiliar with governance and who are finding their way. I think that at that time the media had to play a slightly different role, a more supportive role, more tolerant of poor governance.
- b) A very significant change in our role, as the media, is brought about by the very weak opposition to government in this country. All we have is a DA which yaps about everything and there is no rational approach from them. They do a lot of vote-gaining stuff which I don't think they think through (CW).

I agree that more of a balance should be struck between a surveillance role and a development role (CW).

We are supposed to be the informers and not the judges. We need to put things out there so that people can decide for themselves. When reporting on something like HIV we must impart all the reasonable information available to us (EE).

News policy

Our in-house policy is to try to be an issue-driven paper. You take an important issue and reflect all perspectives on it over time and encourage debate. In terms of trying to broaden the democracy I think we are doing that: allowing people, including those in government, to reflect on different perspectives (CW).

I see the Cape Times' approach as trying to reflect different views (CW).

Every day brings a surprise on any given issue so I like to think the best way to judge coverage is over time and that is how you publish balance (CW).

News values

I'm talking broadly now about news values: I want to be a paper that gives information that you can use to make decisions about your own life (CW).

“The only injunction I have is that *The Cape Times* is pitched at a certain readership level: “aspirational”. We aim at more or less the middle to top end of the market. There is a commercial imperative there. Are we elitist? I'm sure we could do better” (CW).

“One of the more justified criticisms against *Die Burger* (and perhaps other Western Cape papers, particularly perhaps the *Cape Times*) is that we ignore what may interest middle class people – we keep the marginalised communities marginalised. Which we try to change but which is difficult because we are a commercial product. So we need to give our readers what they want to read” (EE).

In a way I do think the news values have become more commercially driven in the last five to six years. We are much more aware that the paper is not there so we can exercise our journalistic freedom the way we want to. There's a very strong commercial element. And I think this plays a large role in determining what goes into the paper (EE).

If I can put it like this: Nevirapine became a political issue rather than a health issue (EE).

The Daily Mail, on the other hand, has done a turn around campaign in the last eight years: they are a magnificent paper, for women specifically. They have turned the traditional news values system on its head. If there is a breakthrough in breast cancer, for example, *The Daily Mail* will lead on it. If I could get them to do that on this paper you would have to buy me a really big bottle of champagne! But they have to start thinking like this here (EE).

[With particular reference to the AIDS conference in Bangkok]:

We do as the media feed into this in a terrible kind of way and there is the inherent tension of “Oh God here we go again, the Minister is questioning the drug, we are at the beginning of yet another political row, maybe we should just ignore it”. But that isn't really our job. She is a publicly elected official and we do have a responsibility to report what she says even if it is nonsense (A).

If you feel a social responsibility then you should go to a reliable science source who says: look what she is saying is patently nonsensical (A).

The role of the journalist in reporting on nevirapine

To give the information as accurately and independently as possible. Record the Minister's views, Zackie's views, the scientist's views. Record all different perspectives.

Journalists are really laypeople who develop an interest in an area and then they sometimes start becoming incapable of assessing other people's opinions. I hate it when they start putting their own points of view across (CW).

When we had her Jo-Anne Smetherton was very, very diligent, very well-informed senior health writer. With her I don't think we did a lot of flashy front-page lead stuff, we did informative stuff because we think it is a very important area. Hopefully this indicated that we weren't pursuing a commercial agenda around health. I don't think you'll find many examples of scare stories (CW).

Generally speaking on the issue of nevirapine I think we did reflect all points of view. I can remember reading the [Health] Minister's point of view. We probably took the mainstream view on it: that she was wrong. I don't write editorials on health issues, but I would have got Jo-Anne to do that (CW).

Generally I would like to think that we have reflected different points of view but we have also had our own views, as reflected in editorials (CW).

In the many news rooms I have worked in my experience tells me that 10 years ago people were very dedicated and actually appointed AIDS writers to write just about AIDS. But today, due to staff shortages, AIDS writers have had to become health writers: health is such a wide field and AIDS subsequently becomes marginalised. The pity is nobody fought for AIDS reporters. The international news agencies like Reuters are doing much better work on AIDS than we South Africans are ourselves. For example *The Guardian* has just done an excellent narrative piece "A Cry for Africa" on AIDS in Africa. We should have done that, we are here, they shouldn't have had to send someone from London. We are missing this story, it is a great one and I am very concerned about it (EE).

Be careful. Be very careful. Nevirapine is an intensely controversial drug in South Africa so uppermost in my mind is to be careful and this means whom I go to for comment and how I write my story and how much context and background I get for my story. I might, for example, write far more for nevirapine than I write for other AIDS drugs. I don't write about all the other ARVS in the same way that I cover NEVIRAPINE (A).

I would also be careful that whoever edits (a news editor or sub-editor) my copy at the other end is aware of the nuances around this drug. We do this by conversations with each other throughout the day. As the day progresses we talk and as the day progresses I update him or her on the development of a story. They then have an idea of whether the story has fallen flat, whether it'll go on the front page and we also discuss the angle. I put a note at the top of my story which will say 'please phone me if you want to change the wording here, it is really important.' Or 'please call me if you want to change the story as it is a very technical piece'. I don't need to do this for every story I write (A).

"I think a lot of the really good health writers simply burn out and leave because of the immense pressure on them" (A).

8 Sources

With this [Valentine] story you could go to a scientist who can say the minister is being misleading, she's fudging, muddled etc, the issue actually is xyz. Nevirapine resistance is not new, she's flying a kite to see what kind of reaction she'll get, they might contextualise it that way: you can put that in the third or fourth para to contextualise it (A).

But the story for us as a newspaper is the politics of it which is the clash between the Minister and the activists, but you're quite right: I think that if you're a patient or consumer wanting information you need that contextualised (A).

There's no one good source: you should go to the Ministry, to the TAC, to the researchers. If you record all the different perspectives through the days and months, then to my mind you are doing a decent job (CW).

I think that there is a lot of single-source reporting on NEVIRAPINE. In SA. I think that in South Africa completely objective and complete reporting on nevirapine is very scarce. There is a whole field of reporting on how and why the drug should be taken which has not been done. I think the problem is that we have left it to the political writers; there are very few health and human interest writers who have picked up on the issue of nevirapine. Coming back to the fact that we can't fill the paper with it and the political guys have been writing about it so much because they made the Minister of Health into this caricature about it. Now as a news editor, for instance, it is my job to balance the paper: so if I get one story about nevirapine, I'm not going to use four others. And I think what has happened is that the political writers have been covering it [nevirapine] so much that the health writers have been sidelined. So I think it is under-reported, the true human drama around this drug, that story hasn't been told (EE).

This is a single source story which comes from a Sapa wire. What Sapa has done here is cut and paste a press statement issued by the health department which contained some factual inaccuracies. They [Sapa] have reported verbatim everything the Health Department said *without* saying 'The Health Department issued a statement yesterday saying blah blah.' So they have not attributed where the information came from, linked to that is the fact that it is a single source story which means they have not gone and checked with any of the organisations quoted how accurate this information is. Now, with a politically-sensitive drug like nevirapine, you need to know that government spins on this one, so you should actually go and check that this is indeed correct. My understanding of the NIH criticism of the Ugandan research was primarily that the research was flawed and that this issue around severe and possibly lethal reactions came from an AP report around the same time. My understanding was that that was not raised by the NIH, but I might be wrong. Be that as it may my concern is that it is a single source story, the information in here is not particularly accurate: it is the kind of story that would make me very worried if I was an HIV positive mother who was shortly to give birth and was contemplating nevirapine because it also doesn't quantify this [not 'is

it safe' but 'how safe is it']. Severe and possibly lethal reactions are possible with almost *any* drug, for example the Pill may bring on a thrombosis while you are on plane flight. So this information is not useful to a consumer. The other thing is that I don't think that are reporting here what the MCC has or has not said is strictly speaking true. I don't think that MCC ever said that sdNVP should be stopped and used in combination with other drugs. So this looks to me like sloppy Sapa reporting combined with an unattributed statement from the Health Department (A).

Try and find different viewpoints, independent scientists to comment, get info from multiple sources (A).

Scientists are known as dismissive and they are also sick to death of this issue and I think they are really, really, really tired of talking to the media and I know that a lot of them feel that what they say is distorted, poorly understood and does more harm than good. This is true of the AIDS dissidence and the nevirapine debate. There are scientists who have just stopped talking to the media (A).

I got the about the MCC contemplating changing the labelling on Nevirapine packs because I happened to walk out of a TAC session three steps behind Precious Matsoso and said to her "Oh what's going on what do you think about the WHO's guidelines for PMTCT?" she said: "Oh by the way we're thinking about banning nevirapine." So she volunteered this information, we wrote the story and she had the gall to say three days later 'oh you journalists are sloppy and you are not doing your job properly'. The generous interpretation of this is that there is a naivety on her part in dealing with the media, the alternative explanation is that this is done with malign intent: they know that if they drop these things in it'll cause more harm. I think it's more clumsiness (A).

9 AIDS dissidents



Generally I would like to think that we have reflected different points of view but we have also had our own views, as reflected in editorials (CW).

I think it is absolutely fair to put forward AIDS dissident view points as well. Freedom of expression is fine as long as it doesn't cross the boundary and become hate speech. If we were to reflect dissident views repeatedly and allow it to become a mainstream coverage on the issue, that would be verging on the irresponsible. But those views, like Riaan Malan's views on AIDS, deserve to be aired (CW).

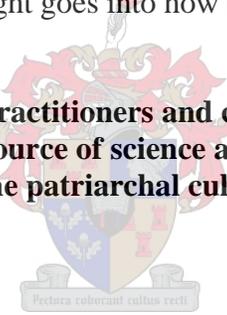
The problem with news is that it is such a fluid thing: A dissident says something, you try to get hold of TAC to get their view but they are not available, [but the story has to go], so the AIDS dissident stories are not always balanced by a science take, but on the whole I think they would be (CW).

I think AIDS dissidents should, cautiously, be given an opportunity to voice their opinions in the media. I don't think it can do that much damage. I think it must be handled cautiously, but I don't think we can ignore the views of not that small a part of

the community. If we ignore what AIDS dissidents say we are not a balanced newspaper, we therefore need to look carefully at what AIDS dissidents say and then present it as rationally as possible. It's our job not to take sides (EE).

Dissident question: this is an issue that I have really grappled with in the last year or so; in fact I have had sleepless nights about it whether to write stories about them. My feeling is that mostly no we shouldn't: we don't give airtime to quacks and cranks. I only write about [breaking health issues] if the material has been published in a peer-reviewed journal (and I know the peer-reviewed process is flawed but is the best source available at the moment), and I don't write about drugs which have not been cleared by the MCC because I am not in a position to assess how safe they are. So why should I be writing about these cranks [AIDS dissidents]? However, when the cranks have the ear of government, when the cranks have the ear of your Minister of Health and your President, then we have to write about them because we need to know who's influencing the people who develop the policies that affect our lives (A).

Given that, there is a huge issue on how you report on a story like this. We have a lot of discussion on how to write it. The decision we make is also based on the fact that our readership is sophisticated and relatively well-educated and therefore able to draw their own conclusions. A lot of thought goes into how to report it (A).



Relationship between media practitioners and consumers (Including issues: Public relying on media as a source of science and health information; View of South African women; How the patriarchal culture affects the spread of AIDS amongst women)

It is a process: in SA journalism we are stuck because we've been faced with this huge tide of crime and volatile politics which have pushed everything else out from the first five pages. I think this why people may not use the paper as an important health source, because it is just not there or if it is it's a week old already because it was just rolled over every day until they could find space for it. Thus I think Huisgenoot or You becomes the primary source of (mal)information (EE).

One of my long-term plans is to get the human story out, because it could literally save lives. It hasn't been done. This is an indictment against the media, because they have left it [nevirapine] to the political reporters and the health reporters have actually done very little (EE).

I think men are more vulnerable to contracting HIV than women. I don't know, I think I might be wrong (CW).

I think the patriarchal culture does increase the spread of AIDS amongst women. I imagine it would: men's refusal to wear a condom, dry sex etc. (CW).

I think we have a very unfortunate circumstance in this country: historically it is very patriarchal. I think the majority of women in this country live in unfortunate circumstances and I think there is a hell of a lot to be done (CW).

No. I would be very, very surprised if the public relied on the media as a source for health information. I think that if they saw something in the paper relevant to *their* health they might then query it with their doctor (CW).

At *The Star* it has always been our policy that, for example, we can write about the squatters in a way that will interest the readers that buy *The Star*. I think the same needs to apply to *Die Burger*: I firmly believe we have to write about whatever is happening in Khayelitsha even though nobody there will ever buy *Die Burger* to read it. But the people who read *Die Burger* must know what's happening there because technically speaking it's their community (EE).

I feel that if right angle is taken, the right message will filter down to those people who don't even actually buy *Die Burger*: people put the articles up on the walls or maybe somebody buys it only once a week, and then there must be something in it. This is my thinking behind this (EE).

Yes I think SA's patriarchal society does influence the spread of HIV. We can empower women through our writing. Which I try to do but I don't know how much of an effect it has. What we need, I think, is a black language newspaper which takes up these issues (EE).

I think the women in this country are wonderful, they are very strong. I think the media still portrays them wrongly by putting them in the paper as victims and not victors. Unfortunately they are mostly victims and you can't really hide this fact from our readers, but: I think we must portray them as survivors; South African women are survivors and I think they are really fantastic. So we are not distorting reality by portraying them as such. Women like reading about other strong women. I get really pissed off if I have to read about how women are the weaker sex when they are not (EE).

Yes, I do think the public relies on the media as a source of science and health information. Maybe, sadly, mostly from *You* and *Huisgenoot*. Maybe because we don't present our health reports in the newspaper as we should: often they 'hidden' inside somewhere instead of making the lead story on the front page. They are treated as softer stories, even significant breakthroughs cannot stand up against commercial news values where murder or accidents take precedence (EE).

Reporting on nevirapine is not consistent because A health reporter on a daily has to cover so much, that is part of the reason. The other part is because the media is very reactive: we are event-driven. This is the huge problem and it is because we are under-resourced: we don't have the time to go digging. But I do agree with you: as a consumer you'd want a couple more paragraphs (A).

There have been times when I cannot get AIDS stories in the paper fullstop. It's AIDS not nevirapine. My editor gets bored with it. Fatigue on the newsdesk. Not as nuanced as a drug like nevirapine. Though, it's more like "Oh God not the activists again, write about something else".

General health reporting standards: good stuff and appalling. What we see is the absence of consumer-driven lobby group for health in general. This affects how we report and where we get info from. This also means we don't think enough of how our readers interpret the stories. I tend to think of my audience as policy makers and business people; even so if I'm writing about a drug, maybe they are interested in it for their mother or sister etc. We probably should think more about those consumers (A).

Recommendations for the improvement of science and health writing

I recommend the use of science writing courses. We have in fact have had courses like that. We have people coming in here and doing that. I get letters from organisations saying we are doing a course, are you interested, and we have done that. We've had people going on courses on about how to report on HIV/AIDS. Most definitely, I don't think you could recommend it highly enough. Because you are not going to find a scientist applying for the job; so you have to look for the right person, personality to cover that area and then I would most certainly recommend that he or she be trained (CW).

What we need, I think, is a black language newspaper which takes up these issues (EE).

My ideal, and I want to introduce it here, are narrative science writers. In America, for example, they have science writers who are brilliant narrative writers. To me, with our strong tradition in South Africa of telling stories, this is how we must do it. I think reporters must therefore be trained in narrative writing as well as in science writing (EE).

So I think it is under-reported, the true human drama around this drug, that story hasn't been told (EE).

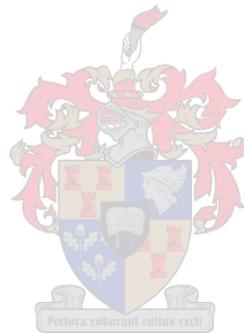
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people who read *Die Burger* must know what's happening there because technically speaking it's their community (EE).

I feel that if right angle is taken, the right message will filter down to those people who don't even actually buy *Die Burger*: people put the articles up on the walls or maybe somebody buys it only once a week, and then there must be something in it. This is my thinking behind this (EE).



APPENDIX N

Government welcomes US nevirapine doubts

December 16, 2004

The Health Department has welcomed fresh questions raised by the US about the safety of Aids drug nevirapine.

The department was responding yesterday to disclosures that US National Institutes of Health officials had warned that Ugandan research on nevirapine was flawed and that severe and possibly lethal reactions to the drug may have been under-reported.

The department said it was working to establish the facts and find medical alternatives to the drug, but public health facilities would continue providing nevirapine as monotherapy to mothers and babies until an alternative was found.

The Medicines Control Council (MCC) recommended in June that a combination of anti-retrovirals be used instead of one dose of nevirapine to reduce mother-to-child transmission.

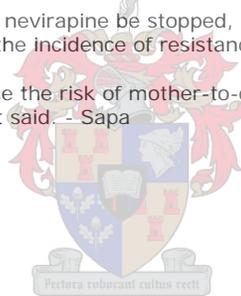
It was concerned about findings that single-dose nevirapine could cause HIV-infected mothers and infants to become resistant to the drug or others in its class.

Its findings were in line with the World Health Organisation's recommendation that combination therapy using AZT and nevirapine was preferred.

The MCC did not recommend that the use of nevirapine be stopped, but said it should be used in combination with other drugs as the incidence of resistance was up to 50%.

This meant the government's policy to reduce the risk of mother-to-child transmission of HIV remained unchanged, the department said. -- Sapa

[\[Email this story...\]](#) [\[Easy Print...\]](#)



APPENDIX O

Four journalists were interviewed; Di Caelers of *The Argus*, Willemien Brümmer and Johann de Villiers of *Die Burger* and Kerry Cullinan of Health-e. Their comments were sorted into the categories outlined below.

The categories were defined by both the researcher's original questions and additional issues that arose during the interviewing process. Comments are recorded with the initials of the relevant participant (in this case one of the four journalists interviewed).

Categories

Are journalists of the opinion that the media is perceived as a true reflection of reality by the public and if so is the media an important science source for the public?

According to studies, as far as I have read, up to 70 % of them believe what they get from the radio (KC).

Yes, I think they do believe what they read and I think that that is what makes it so intimidating. Reporting per se must always carry both sides of the story; but with ARVs there is the obligation of scientific authority otherwise if you don't you report on something which is not scientifically respectable and in so doing cause a lot of damage, especially in health writing where it a question of life and death. People will believe what you write. (There are still people who believe that if you have sex with a virgin it will cure you of AIDS.) (JV).

I think that they are often very confused by the mixed messages they receive (WB).

Because people believe what they read in the newspaper, they are naive. I think Jo average does, and that is why, as a journalist, you have such a responsibility in passing information along (DC).

Media as a source of health information for the public:

Again, according to studies, yes (KC).

Yes (JV).

Yes (WB).

I think they probably do if you are talking about all media, especially radio. This is why it is so important to do the job well: these people do not have any other access to the information through the Internet, libraries etc. Or maybe they are simply not educated enough to go and seek out the information for themselves. (Tie in with relevant research quote on this very issue in the literature review). Further more these are the poor people

who will sit in line all day at a clinic to get treatment from a doctor who is not going to give them an extra second of their time to explain things in detail. So where else are they going to get their information from? Either from the media or other people who have, perhaps, got their information from the media and so on (DC).

Function as a journalist when reporting on nevirapine

To give as up-to-date information as possible on treatment for the prevention of PMTCT. I think it is also important to investigate other treatment options. Also controversies but with a science viewpoint (KC).

I think of how political it [nevirapine] is. You are far more aware of this than when you are reporting on other ARVs. You immediately that what you say is going to have a political consequence. So maybe what happens is that you oversell it, to a certain degree you become a nevirapine. Crusader because you know it is a good drug and that nobody in the scientific community denies this. If you are working against such political odds, we have to convince the people that this is the best way to go. And I feel that the message isn't always getting through, [because of the political nature of the drug] and this is a shame. Also you can only say it that many times, people get tired of hearing it all the time. You don't want to become one of those activist journalists but just by being true to scientific respectability (which is vital to health reporting) you automatically step into the arena of political activism. AIDS is such a political issue, nowadays if you are health reporter you spend time in parliament and go to political rallies because the big story is a political story. I probably speak more to the health spokesperson of government and the health spokesperson of the DA than our political reporters do and I don't think this is the way it used to be. It's just AIDS that does that (JV).

To be very clear because there was a lot of conflicting information out there (WB).

To explain it as simply as possible to them so that they can understand it. Correctly relate issues that the public needs to know about. With something like AIDS, which news editors find a very unsexy subject, you have to find ways to report on it that is interesting. At the moment I am working on a project about whole families who are affected by AIDS. How they actually live with it: when you report on HIV/AIDS try and bring it as close to yourself as possible, make it so other people who are not affected by it can identify with it. What it's like, as a woman, to support three children with AIDS with no husband who has either died or left you. (WB)

People are also too shy to write about sex which is the main way in which the disease is spread. Nobody writes about how middle class white Afrikaners practise unsafe sex and how rapidly the disease is spreading there (WB).

I think your job in the media is to keep trying to make the subject interesting and trying to relate it to everybody, personalise it for your particular group of readers. If you only write about very poor black people your readers are going to lose interest and they will not

relate it to themselves when their own children are, in fact, out there practising unsafe sex (WB).

I feel I have two roles: to enlighten people on issues they knew nothing about before and to educate them (DC).

But people are incredibly ignorant of what is out there in terms of their health. Especially those from formerly disadvantaged communities. They tend to just believe what the doctor says although I feel this is changing slightly with the use of the internet. They do their own research. But there is still the “us and them” perspective where people think the doctors have been to university so therefore they know what is going on. Therefore in my role I see it as important to break down the blue sky science, and it really is as far removed as blue sky science to some people because they just don’t understand it at all. I try to bring it down to grass roots level to make it more accessible (DC).

The other side is the political aspect. Health is often politicised. So my function is to educate and inform. I do a lot of analytical stuff as well, especially on the controversial issues (DC).

...because as a journalist you present different sides of an issue and thus let people choose. But with things like this, where people will die if they stop their ARVs, you have to have more of an activist role. I feel this social responsibility greatly (DC).

Should the opinions of AIDS dissidents be voiced through the media

We would not do this generally because they [AIDS dissidents] have been discredited internationally. We do sometimes, however, because they are in contact with the Department of Health and if the ministry gives them voice, so must we (KC).

For example if you report on ARVS as the best treatment available for AIDS and then also put across the opinion of an AIDS dissident like Matthias Rath : by the standards of political reporting you would be acting ethically but you would really be causing a hell of a lot damage (JV).

Even if you report what Rath says, and then shout it down immediately afterwards people have already read that and actually got stuck at what he said.[insert Mitch’s comment here as well on ‘people remember the bad, not the good’] you have to be very careful about what you write even if you balance it with the other view (JV).

I don’t think AIDS dissidents should be given voice in the media. The problem with Rath is that he is a tireless marketer and had obtained an unfortunate degree of backing from the Dpt. Of Health that we had to start reporting on the issue, not necessarily by giving him a voice but rather to address the issue that now he does have a voice how do we go about reporting on that. For example Anthony Brink is bringing out a new book and he feels sore about the deliberate attempt of the media to not give it any exposure. In a sense

he is correct, the media is not giving him publicity but I think it would be highly irresponsible to do that (JV).

I think it's a very thin line. Coverage of them glorifies these dissidents, even negative coverage is coverage. The less you write the better (eg. Raping a virgin myth, people took it seriously even though it was reported as a myth: We report on the weird things that Manto and Mbeki say about AIDS and the public then has a very confused impression on AIDS, then the public think this is the honest truth. It also glorifies them even if it is critical. It is a sensational take (WB).

I think those people shouldn't be given space in the papers because I think it helps spread a view that perhaps it is better people don't know about. But at the same time if something is going on in court (like the Rath case at the moment) it is impossible to ignore it because you are depriving people of knowledge. But I wouldn't give him publicity not because I know he is wrong (I am not a doctor), but because people who I trust, who have standing in the medical field and have an opinion of Rath: I would take my lead from them. There are not many health writers in SA and we mostly know each other and I think this is a feeling that is shared by most of us. Because reporting on HIV/AIDS is very personal, you are talking to people who are suffering: you cannot say I am going to report everything I hear, because you may create damage by doing that, by saying I'm going to be completely unbiased (DC).

As a health writer you have a responsibility not to spread this, at least not any further than you would have to: we would have to report on Rath walking down the street handing out his vitamins if this was the case. But a way around it is not to report on it straight but to get other people to comment on it and give it context (DC).

Sources

It is also important to present nevirapine controversies but to balance them with the back-up of a sound science source (KC).

It very much depends on the story: If it is a human interest story I would only use a public voice and no else. For a report on treatment, I would use an HIV patient and their doctor to comment on their condition. If it were something to do with the PMTCT programme I would use the Department of Health. I would use TAC as a source for a community angle, never as a science source. Disagreements between government and TAC would not be balanced by a science source unless the issues discussed were of a scientific nature (KC).

Monitors have been looking at our work and it has been decided that we need to include the more ordinary voices of people who are directly affected by AIDS. These monitors included UNAIDS and media academics (KC).

[I don't use community voices when reporting on NEVIRAPINE or AIDS issues] enough. Willemien has done that well. Much of the community voices get channelled through TAC before they get to you, which is not really then the pure thing. This is definitely a gap in my reporting which I need to address. We should be doing more storytelling, more features, we need to work on that, so people can share and learn from each other by providing positive role models.

I never use a study unless it is peer reviewed and I check up on the person who wrote it. I would never submit a story on nevirapine without first OKing it with a science source I trusted. You cannot trust your editor on health issues because they often have a very poor understanding of the issues.(WB).

I use them (community) as often as I can, otherwise the story is too bland: you have to put a face to it (WB).

A lot are women because 80 % of the patients at AIDS clinics are women. The caregivers at the clinics are mainly women: if there were more men, more male patients might present at the clinics (WB).

Because reporters have daily deadlines they use information that is spoon fed to them, that is easily available. And they are not critical enough about the information (eg with AIDS dissidents) WB.

You have to be really careful and make sure that your sources are impeccable. I try to use a source that is an ARV doctor, rather than the TAC. Although I do trust the TAC and I think their credentials are good, but I think that in AIDS dissident context, for example, it is better to go to an ARV specialist of which there are loads at Groote Schuur Hospital. They are activists as well as doctors (DC).

When I use TAC as a source I find my writing becomes drawn into a political debate. They are at the forefront of the politicisation of AIDS, they are very outspoken and they are almost like rent-a-quote, they do give fantastic quotes. If you are working on deadline this is very appealing: let's just get TAC. They do have a very politicised angle to things because this is their cause.

Health writers use TAC because of their accessibility, not because they would rather but because they have a deadline to meet (DC).

It is difficult to use the public as a source for a science take on nevirapine. You can interview a mother whose baby has been saved by nevirapine: good human interest, success stories are good but you cannot do this over and over. You have to be quite careful about using that. It is the same with everything about AIDS, you can't keep doing the same stories over and over, it's difficult to keep people intrigued. Our own in-house research shows that people don't read the AIDS stories. Sales figures drop when we lead with AIDS (DC).

Nevirapine was such a scientific issue and we did cast the net wider to look at mothers. A mother's voice is a very emotional one "you saved my baby": there is nothing more powerful. But this is a limited voice you can use because the angles are limited.

With regard to stigma things have changed a lot: Up until 2003 there was enormous resistance to being named as an AIDS patient. Now that has changed and this is largely due to TAC because these people are HIV positive and they do speak out. It is disclosed to family and they agree to being photographed. The impact of a photographed face is big. Before 2003 we were using a lot of anonymity and it just does not have the same impact (DC).

But if I don't understand things I always ask the scientist, because I cannot run the risk of passing on flawed information. The researchers are happy with this and you need to build trust between yourself and your science source because if you don't those people will never come back to you. I also often send technical science articles back to my science source to check once I have written it (DC).

AIDS is such a political issue, nowadays if you are health reporter you spend time in parliament and go to political rallies because the big story is a political story. I probably speak more to the health spokesperson of government and the health spokesperson of the DA than our political reporters do and I don't think this is the way it used to be. It's just AIDS that does that (JV).

A lot of politics: if Manto said something it was immediately construed as bad but if TAC said something it was immediately seen as good and journalists just kind of accepted this, I did it as well. TAC are the good guys but at the same time a lot of the media had lost their ability to analyse critically what they [TAC] were saying. The media did this because they were not scientists themselves and they need somebody to rely on. And TAC is good at explaining very technical issues. Whereas gvt. Does not try to simplify things and relate issues in an inaccessible way (WB).

Relationship with readers including perception of women in South African society, including effect of patriarchal culture on spread of AIDS amongst women

No not to the extent that I would have expected, our policy has not interfered with the flow of my stories: Die Burger has the theory that AIDS is the big news story in the country and we must cover it from all aspects. I am happy about this because if I were writing just for our readers (middle-class Afrikaans) I would be skipping a lot of these issues. There is always space for more (JV).

Yes. [Patriarchal society does affect spread of AIDS amongst women].
In this country women are the unsung backbone of community life and raising families. They are economically and culturally disadvantaged but they are the ones who hold communities together (KC).

Gender inequality does spread HIV virus. Men have multiple partners, women are not empowered to negotiate when and how they have sex (JV).

I think the majority of women in SA are unfortunately not reaping the benefits of gender equality as seen in on government level and I think AIDS is pushing this back even more (JV).

Instead of paying attention to the important science at the conference the media had to retrack on what it had said originally about the deregistration of sdNVP. So the whole thing was blown out of proportion by most of the SA media, especially Business Day. Jumping to conclusions like that can really confuse issues in the public's mind (ref. back to answer no. 1). TAC and the gvt. Behaved like children instead of having an adult conversation. So journalists reported on all this instead of on the real science issues around AIDS (WB).

Yes AIDS is spread amongst women via cultural inequalities. I feel a lot of sympathy for them (WB).

Resistance caused by single dose nevirapine, also toxicity, less toxicity if more drugs are used (WB).

What was uppermost in my mind was the possibility that children could die if sdNVP was withdrawn. I was speaking to a load of people in 2002/3 who were seriously, seriously anxious that it was going to be withdrawn. Dr Glenda Gray from the Chris Baragwanath Hospital said to me "Nevirapine may not be a first class ride for HIV positive pregnant women in South Africa, but it is an economy class ticket that scientists and medical staff across the country believe is the best chance in beginning to address the paediatric AIDS pandemic". This really meant something to me because people were saying "give us something". It was quite scary (DC).

Yes, an enormous influence. Women have so little choice in terms of their sexual relationships. It is, therefore, important to do gender and culturally sensitive reports. To give those women a voice is a most fantastic thing. To do it in a positive way is even better, the success of business workshops where those women make and sell things, to portray them in this light really builds them up and make them feel special for a change. Instead of being downtrodden all the time: when the men learn their woman is HIV positive, they leave them on their own to bring in the money, look after the children etc. This affects every facet of their lives: how they work, where they live, future relationships: they are definitely carrying the burden, no doubt about it (DC).

The women are very adamant that they don't like to be portrayed as victims: but it is a difficult one because when you portray them as a victim more people will react and help. But this kind of help does not empower them which is ultimately what we want to see. Here the success stories are good: they put them up on the walls of their workshops: so even if these people aren't buying the paper, the message does spread through the

community. For example people looking for work wander into a workshop and they see these stories on the walls (DC).

The women involved in township workshops are such a strong bunch: they would turn this country around in no time, if given the chance. They just put their heads down and do what has to be done. They smile, laugh and have fun and it is wonderful to see. It is very uplifting amongst all the misery that you do find (DC).

When reporting on AIDS issues we try to present the positive. People do not have to be presented as victims in order to elicit help from others: people often want to contribute to craft workshops for example. Be sensitive in your reporting, present their success along with their difficulties (DC).

I think there are some very good health writers in the country, eg. Health e, but a lot of the good ones have actually left the country. They have enough and go: it is a heavy job because it can be very emotional, especially when you are dealing with AIDS issues and some journalists just can't take it any more. The voids are then filled with people who do not know enough and this is dangerous (DC).

Scientific and clinical knowledge of nevirapine

With reference to the recent Lynne Morris study where it is suggested that there is as much as 80% resistance to single-dose nevirapine, I am concerned. The drug should therefore be seen as an emergency measure as in the event of a late presentation at a clinic just before giving birth. If it is not used carefully it may jeopardise a future ARV programme for the patient (KC).

Single dose nevirapine causes resistance (KC).

As a treatment for PMTCT, NEVIRAPINE acts as an impermanent shield to prevent the spread of the HIV virus. It is almost as though it "coats" the baby's cells (KC).

SdNVP as a treatment in SA, I'm not well-enough informed to tell you that, I would have to refer to a specialist first (JV).

SdNVP creates resistance, I think (JV).

Combined therapy causes toxicity (JV).

No I am not comfortable in my knowledge of how NEVIRAPINE. Operates (JV).

SdNVP interacts with the transfer of the virus during the birth. So as the baby is coming down the birth canal it interacts at that point, then the baby is given another dose ten days later which will then "mop up", basically it's a mop up arrangement. That's because when the baby's there is huge chance of the virus being passed on through all the body fluids involved in the birthing process. If you add AZT it gives that added kick (DC).

Aside: When you are a health writer people think you know everything but you don't. It's not like in America where scientists or doctors become health writers, we don't have this in SA and it is a huge learning curve to cover health, especially with AIDS because you have to become an expert for a while. (DC)

SdNVP causes toxicity, less toxicity if you use more drugs
Baby gets spoon of NEVIRAPINE. Syrup within 24 hours of birth and the mother gets a dose when she goes into labour. (WB)

Opinion on AP reports in Dec. 2004

It caused a lot of unnecessary alarm: there were administrative problems – there was nothing wrong with the efficacy of the drug. But at the same time I sympathise with the journalists because the NIH are hard to reach for comment and the journalists probably had to run the story for deadline. I have a deadline for tomorrow and need a comment from the NIH and if they don't come back to me I will run the story anyway (KC).

It was a shame because it set the debate back. I know the problem was more an administrative, procedural problem which did not affect the validity of the study. I think, however, the findings would have been more powerful if this hadn't happened to throw a bad light on it. You would not be able to use those findings with confidence now because of what went wrong there which is a shame, I think. I don't know enough about it but I know I wouldn't go around quoting that study now (JV).

(Didn't know anything about it, but agreed that it is irresponsible reporting) (WB).

I think that that kind of reporting can be terribly irresponsible. Although the HIVNET study has been questioned over the years medical experts have always supported it: the problems were, after all, administrative. It's all very well getting a front page story saying the study was flawed but when mothers refuse to take the drug (Like with the Rath thing at the moment with people refusing to take their ARVS) you are doing the whole world an injustice, these kind of stories HAVE to be balanced. Within the context of a pandemic like AIDS irresponsible reporting like that really does not help at all. Maybe you can report like that with other things but not HIV/AIDS. Like Rath: if you take ARVs your life will come back to you. It's a huge responsibility to write about HIV and I don't think just anybody should go out and do it (DC).

Science writing training for journalists

No I have done no science writing training: I have been learning on the job. The newspaper does not pay for me to go anything, but sponsored workshops have been arranged by major pharmaceutical companies for example (JV).

None. I am self-taught (KC).

The paper does not offer health writing courses but I was lucky: Before the 2000 Durban AIDS conference a pharmaceutical company ran an AIDS information course for journalists which really formed the basis of my knowledge about the disease and equipped me to write about it (DC).

Recommendations for improved health reporting

I think Tamar Kahn is the best health writer around thanks to her scientific background. In fact I think she is the leading science reporter in the country. I got into health writing through the Arts. I think there should be a general science-writing training for all journalists as even editors don't understand what a peer-reviewed article is, or what the difference between a bacteria and a virus is. The idea of a science desk is totally unrealistic in this country, so all journalists need a basic training in health/science writing. An example of this dilemma is seen with the Cape Times whose health writer has now left. They are not going to replace her because I don't think they can afford to. The Cape Times relies on us now and they want daily reports which is unrealistic as we don't do that, it's just not in our policy [as it jeopardises the quality of our health reporting] (KC).

Improvements in health writing in general: there's a need for more in-depth feature writing, research and development issues. We are trying to get around to that but it is hard with the workload you have as a news reporter in this country. At the moment you have to sell it as having an immediate effect (something you can go out and buy or get from a hospital); some political implication which is a shame as it would be nice if we could do more pure science. That's the reality we are dealing with at the moment (JV).

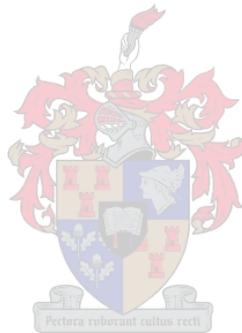
Also because medical issues are often very complicated and you really have to work yourself into them. I don't think you can have people reporting on AIDS and other health issues, you need specific AIDS reporters. I think your news editor should have much less control over what the health writers write, much less than with other less scientific subjects because often they just don't understand the issues. I think you should constantly go to workshops. George Claassen was very good about organising it and I also often asked (WB).

It would be really cool if you could have reporters working with people like me who have been doing it for a long time so they can be trained up, but the constraints just don't allow for it. We don't have, like in America, six people working on a science desk together who can offer a knowledge base for those people coming up behind (DC).

I think this is something we have to work towards in the future even if it is an unrealistic expectation right now (DC).

Health can be a mine field to work with for somebody who doesn't know what they are doing (DC).

Because health is such a huge area with diverse aspects: the political, the health, the research, human interest. I feel as though I am constantly chasing my own tail (DC).



APPENDIX P

A fall of sparrows - Part 1

October 8, 2003

Report by Nalisha Kalideen. Photographs by Debbie Yazbek.

The roller-coaster lives of Julia and Peggy, and the final journey that has taken them to the place where they face their moment of truth.

Like the wings of a bird fluttering in the wind Julia's hands reach out from under her blankets as she recalls the good and bad times of her life.

Shrouded in a blanket, Peggy hides from the world, the pretty curtains and cushions and the ornate bed symbols of her yearnings for a better life.

For only a penny you can buy two sparrows, Yet not one sparrow falls to the ground without your Father's consent Matthew 10 verse 29:

The words from the Bible that inspired the name Sparrow Rainbow Village, an Aids hospice in Florida, west of Johannesburg.

This is a story of two women, one 40 the other 31, whose lives have been hard, a story of hunger and cold, and rape and anger and despair, and love found and vanished, and hope kindled and dashed.

And this is a story of courage - for neither woman has lost her spirit. There are still flashes of fire and humour, and there is love and caring for their children - and the worry of what will happen to them when they are gone.

We met Julia and Peggy through a woman who works in Lawley, a squatter camp west of Johannesburg. She told us she suspected both were HIV-positive. If you want to write about them, she said, remember they are people, not just statistics of a national tragedy.

We have tried to heed her words, getting to know Julia and Peggy and their families over the past few months. We have spent many hours in their shacks and watched them grow weaker as they fought their sickness, hunger and the winter cold.

And we followed them on their last journey, to Sparrows, a hospice on the West Rand where they found love and care as they waited to hear the results of their Aids tests.

This is the first of three parts of A Fall of Sparrows, possibly the longest single report The Star has published. We believe this chronicle is far more than the tale of these two women - there are a million Julias and Peggies in our midst, and this is their story too.

We have called them Julia and Peggy to protect their families and we have used their first names throughout. That is how we came to know them, and they us. - Nalisha and Debbie

JULIA'S STORY

The years of pride and a job and love and hope and health

In the years before the curse, her life was better. Julia was beautiful, she had admirers and lovers, a job, her health, her pride É and some hope.

Now, late on a bleak winter's evening, 40-year-old Julia has arrived at Sparrow Rainbow Village, an Aids hospice in Florida, 20km to the west of Johannesburg. For most who come here, it is a place of love and care, of faith and, perhaps, of hope. A good place to die - better anyway than a cold,

wet, wood-and-corrugated iron house.

A few hours earlier, Julia was shivering in her rusty, rickety shack in Lawley, a settlement south of Lenasia.

Winter rain had leaked into the room, dampening her already rotten blankets and leaving her so cold and ill that the fire inside wasn't enough to warm her.

Sick and weak, her body little more than skin stretched over bones, she huddled under layers of clothing and bedding. She doesn't know exactly what is wrong with her, but she knows it is from a curse placed on her by a sangoma.

Now Julia's time to leave, and move to Sparrows, has come.

So it is, too, for Peggy, whose shack is close to Julia's. They have never met, but Sparrows will bring them together, briefly, not as friends sharing common loves and interests, but as two people bound in adversity.

Peggy has spent her last nights at home like Julia - miserable, cold, and lying in bed without the strength to get up and eat the few scraps of food in her shack.

In one of her many moments of helplessness and frustration she said, and not for the first time, that she didn't want her son anymore.

Peggy arrives at Sparrows a few days after Julia. She's still as bad-tempered as she was in the misery of her shack and she's still howling complaints about her niece beating up her son.

Like Julia, Peggy doesn't know yet that Sparrows is for HIV-positive people only. Nor does she know if she is HIV-positive and Sparrows needs to be sure of her status as soon as possible. So Peggy settles down to wait as they arrange to take her to Helen Joseph Hospital for the tests.

Although strangers, Julia and Peggy have a link: Cora Bailey, a grandmother with cornflower blue eyes, cropped blonde curls and delicate creases around her eyes.

Cora, a strict vegetarian and a fierce animal lover, first went into the West Rand townships in the early 1990s to look after dogs and cats.

Today she finds she's caring for as many people as animals. In countless homes in these squatter camps, Cora is the only hope.

"These stories need to be told because they are the forgotten people," she says.

"It's the very sad part that everyone thinks of them as statistics. Everyone forgets that there is a real human being with hopes and desires."

The people Cora brings to Sparrows are the sickest of the sick, those whose chances of survival are slim. And she knows that when they die she will be the one who has to tell their families. She admits she cannot cope with this.

Cora met Julia earlier this year, helped her regularly, and was so shocked by her condition that she made the family a priority.

By mid-July, she believed Julia had Aids.

Now Cora is terrified that when the rains come, Julia will die in her shack. So she has called up Sparrows and they have told her to bring Julia to the hospice.

As for Peggy, Cora stumbled across her a few months after the woman's 18-month-old baby Vuyo had died.

Peggy was in such a deep state of depression that she would hardly speak. She was not working and there was no money in the home.

So Peggy, her son Dumisani (11), her niece Letang (18), and Letang's son Tony (2) had to rely on the kindness of others to survive.

Cora began giving the family donations weekly but Peggy deteriorated and a few days after Julia's arrival at Sparrows, Cora takes Peggy there too.

Julia doesn't know it, but Sparrows could be the place where she spends her last days. She's been stick-thin for several years, her thighs just marginally bigger than her arms, and her conversation is punctuated with violent phlegmy coughing that makes her whole body shudder.

Julia doesn't believe she has Aids, but she's prepared to stay at the hospice so she can be healed and return to her home and children.

She thinks her illness has been caused by a combination of flu and the sangoma's curse.

In the years before the curse, Julia's life really was better. Her memory of those early years is fuzzy and confused and it's Julia's daughters, 20-year-old Elizabeth and 15-year-old Lydia, who have to remind Julia even of her brothers' and sisters' names.

Julia was the second child and second daughter of a family living in Jachfontein, a small mining community just south of Lawley and Elandsfontein. She was followed by three brothers and two more sisters.

She barely remembers her father, who left the family when she was young, but her memories of Jachfontein are happy compared with the years to come.

"I worked at all the mine houses. I'd wash and make the house clean and I looked after the children. I'd wash their clothes and bath them because their mother would come home and want me to have washed them," Julia says.

She remembers working for a woman who had a little daughter but says that after three years she was fired.

"That machine which polishes the floors broke. They got angry and said I broke it. It wasn't me but they said I must leave the job."

She is still proud of her work. "I worked and I worked well. They didn't pay well but that's work. I used to iron so well they used to think I worked in a laundry," she says proudly.

Her daughters say that, back then she was a beautiful woman, with full hips and trusting hazelnut brown eyes.

Signs of it still show in her high cheekbones, her sparkling eyes and the unblemished face, which, surprisingly, has withstood the ravages of her sickness.

When Julia was 20, she met the first of the four men who would father her four children.

First-born was Elizabeth. Five years later came Lydia and, when Julia was 27, she had Christopher, now 13.

About 11 years ago, Julia moved to Lawley and it was here that her last child, Peter, was born. Her looks attracted many admirers and lovers, but no husband. All four of the fathers drifted away and she can't remember any of them with much clarity.

None of the children remember their fathers either, but they do have vague memories of the men who came afterwards and treated their mother well.

There was Joshua, who lives in Lawley and who from time to time would come with presents, and Simon who also still lives nearby and who also treated Julia as if she were special.

Peggy was special too. Unlike Julia, Peggy doesn't have to rely on the memory of her relatives to attest to her once-upon-a-time beauty - she has a few faded photographs of herself as a 20-something-year-old girl.

Check the pictures from the past against the face of today's Peggy and you get two very different portraits.

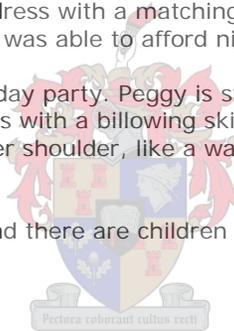
Frozen in the photographs is the smiling face of a good-looking young woman, with full hips, a round face and a wide smile.

In one, she's dressed smartly in a red dress with a matching red hat - she says she was a smart dresser then and was able to afford nice clothes.

In another, she's at her nephew's birthday party. Peggy is standing in front of a shack, wearing a powder-blue dress with a billowing skirt, holding the cake balanced in her right hand near her shoulder, like a waitress carrying a tray.

She's smiling broadly at the camera, and there are children everywhere in the background.

Fast forward to today's reality.



What turned this smiling beauty of 20 into a 31-year-old woman who can now snarl that she doesn't want her son?

Peggy's memories of her life and past are only slightly clearer than Julia's.

She knows she was born in Diepkloof, Soweto, but doesn't remember exactly when she moved to Mafikeng and then back to Diepkloof.

Nor does she remember her father who left when she was small. Peggy says if she saw him now she wouldn't recognise him at all.

She remembers her mother, her brothers and sisters clearly but she cannot remember how old she was when her mother went back to Diepkloof and left her and her younger brother Washington and sister Constance in Mafikeng to live with another family.

She attended and finished primary school, but did not go on to high school - back in Diepkloof her mother was trying to support her children on her own and there wasn't enough money to keep her in school.

Peggy has no regrets about this. She never dreamed of being anything in particular when she grew up - not a doctor, or a nurse, or a

teacher.

All she wanted was a job.

"Me, I just wanted to work," she says. "Didn't want to be something. Just wanted to work."

She remembers moving to Diepkloof around 1990, when she was in her late teens. She lived with her mother and sisters and started working nightshift washing dishes at a restaurant in Randburg.

When her mother became ill in 1991 and had to be admitted to Chris Hani Baragwanath hospital, Peggy met Sthembiso - the man who was to change her life.

JULIA'S STORY

The years of pride and a job and love and hope and health

The four men who had the greatest impact on Julia's life passed through very quickly, but they left her with her greatest joy: the four children she would always love so dearly.

Now these men are shadowy figures, and there are no clues as to what they looked like, such is the dominance of Julia's genes in her children's looks.

What sort of mother was Julia? Her eldest, Elizabeth, talks with affection about Julia's fierce devotion to her and her siblings. They needed it, for even relatives would make fun of them for each having a different father.

"My aunt would call us potatoes, tomatoes, cabbages and eggs because we had different fathers," Elizabeth recalls. "My mother would get cross and shout at her."

Both Elizabeth and Lydia chuckle over the memory. It wasn't just a protective love Julia felt for her children, but a playful love too. "My mother used to hug us and say: 'Kiss me here'," Elizabeth points at her cheek, smiling.

Life was about as good as it was going to get for the family. Julia was working and there was money for food, and sometimes clothes.

Her shack, which rested on a hill across the road from the main Lawley settlement, was compact, with two little bedrooms separated by curtains nailed into the timber frames and a small kitchen area.

There was a kitchen sink that rested on two tin buckets, two beds with steel frames and even a grey ceramic vase with red plastic roses, and a little wooden box in which they would store their valuables, such as they were.

Julia recalls that, back then, she would keep her shack as spotless as the homes of the people she worked for.

Elizabeth also remembers that time well. Her mother would come home with money for food and clothes. And it's the memory of being able to buy the clothes of her choice that remains foremost in Elizabeth's thoughts.

"Things were better. We were suffering but not so bad. Now we don't have the money to buy clothes, only what people give us."

Of Julia, Elizabeth says: "She was good a mother. When I was sick in bed - before I had the baby - my mother would go collect tin cans (for recycling) and sell them. She would buy bread with the money."

Suddenly she and Lydia remember an incident and they both start laughing, their heads ducking down, their shoulders shaking. Elizabeth laughs so much that she starts to cry.

Lydia starts to explain. It was a few years back, after Elizabeth had her baby, when Julia started to get sick. They had no money and no food.

Julia had gone to Ennerdale with the hope of finding something for them to eat. She had scrounged in the bins outside the houses, but all she could find were rotten, burned bananas.

"She brought them back for us. She said, 'You will eat or you will die'," Lydia says laughing.

"We ate it. The baby also ate it," Elizabeth laughs. "There was no other food."

Did they laugh about it then? We don't know, but they do now, perhaps rather at the memory of a time of imagined happiness rather than the reality of burned bananas.

Meagre, and short-lived as these years were, Julia and the children still look back in fondness at a past when, by their measure, even the bad times were good.

But they were not to last. Not with the coming of the curse.

Peggy doesn't remember exactly when she met her lover, Sthembiso, but it was while he was working at a mini-market across the road from Bara.

She fell in love, and she fell pregnant. They never married and when Peggy heard from Sthembiso's brother that he had two wives back in KwaZulu-Natal she left him.

But by the time Dumisani was born, in May 1992, Peggy was no longer working and she feared for her baby's future.

She tried to get Sthembiso to support them but he gave her money only occasionally so she continued to stay with her mother and sisters, who helped her and the child.

Though Sthembiso couldn't, or wouldn't, support Dumisani it didn't mean he had no interest in his son. Peggy remembers him wanting to take Dumisani back to KwaZulu Natal with him.

"I said: 'No, you didn't pay lobola, and didn't give money for baby clothes. Now you want Dumisani? I say no.'

"When Dumisani's bigger he can go," Peggy told him.

Though her relationship with Sthembiso hadn't lasted, Peggy was young and still attractive.

At 24, still living in Diepkloof, she met Thulani. They were occasional lovers, but he eventually left her for another woman.

He also left her pregnant and she had a baby girl, Tebogo, in August 1996.

Thulani didn't know about the baby and Peggy never told him - not even after Tebogo died from pneumonia when she was 4 months old.

"Was nice this baby, was so big," Peggy says fondly.

She worked at a take-away in Braamfontein until just before she gave birth and she blames her employers for Tebogo's pneumonia.

"I was working until I was nine months pregnant. I would pack the fridge and mop the floor. When I told my boss that I didn't want to work by the fridge he said 'No'.

"When my baby died, I went there and said: 'My baby's dead and it's because of you'.

"I stayed alone for a long time after that," Peggy remembers. It was four years later, soon after she had moved to Lawley that she met her last boyfriend - Vincent.

They lived together for two years in the single-room shack she kept spotlessly clean, shining her aluminium bucket and bread tin until she could see her reflection in it.

Everything had its place in Peggy's house: the clothes hidden under the bed, the plastic containers put in the corner near the sunken sofa, the food stored in plastic buckets and the bread tin.

She wasn't working then, and neither was Vincent, but they managed to survive.

But she remembers it as an abusive relationship. He would beat her and sometimes threaten her with a knife or hammer.

"I was sleeping in bed one night when he did this," she puts one hand across her throat and raises one hand above her head to show how he would threaten her with the knife.

"When I tried to grab the knife it cut my hand," she says, and shows the palm of her hand.

Dumisani, who was about 9 at the time, would witness these fights.

"When he hit me, he would hit Dumisani because Dumisani would fight with him (to stop him beating her)," Peggy remembers. Perhaps not surprisingly, Vincent was soon arrested for possession of an illegal firearm. And despite the beatings and abuse, Peggy cared enough - or feared enough - to borrow R1 000 to pay his bail.

He showed his appreciation by skipping bail and fleeing, Peggy thinks, to Transkei and then to Cape Town.

By then Peggy was pregnant with Vincent's child, but she didn't try to find him again to tell him. She wasn't surprised by the pregnancy because Vincent had never let her use any sort of contraception.

"We didn't use a condom. Vincent would hit me when I asked him to use a condom. He don't want to use - he'd ask why must he use a condom? I would say I come from another man (Thulani)," Peggy says.

By then her sister Constance, with whom she had grown up in Mafikeng, had died. And her sister's 16-year-old daughter Letang was also pregnant.

"I was pregnant but we didn't know Letang was pregnant. They noticed at Constance's funeral and when we took her to the clinic she was six months pregnant.

"The baby came at seven months. I took the nappies and all the clothes I had got for my baby to Letang because she had no clothes, nothing for the baby," Peggy remembers.

And even though she wasn't working, and was pregnant herself, Peggy took in Letang and her newborn son, Tony.

And soon Peggy had her second son, Vuyo, who was born in July 2001.

She applied for a child grant and spent the money on her new family, paying for Letang's school fees, buying clothes and, most importantly, food for the children.

She must have been happy then, for Letang recalls: "She was nice all the time, she was laughing and had many friends."

And Peggy adored Vuyo. "She liked her baby too much. She did so many things for the baby.

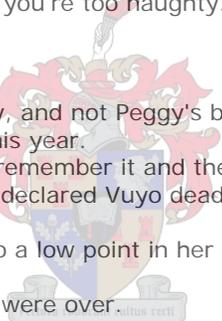
"When she went to sleep she would take the baby with her. She'd tell Dumisani: 'You're not my baby anymore, you're too naughty.'

But he liked the baby too," Letang says.

But it was Letang's premature baby, Tony, and not Peggy's bubbly fat Vuyo who survived. Vuyo died at the start of this year. The date is sketchy because Peggy can't remember it and there is no death certificate because she never declared Vuyo dead.

But it was after his death that she sank to a low point in her life.

For both Peggy and Julia, the good times were over.



A fall of sparrows - Part 2

October 9, 2003

By Nalisha Kalideen

Part 2: The good times are over for Julia and Peggy. This is the story of millions of women and their battle for survival

Where has all the beauty, and body, gone? Stick-thin Julia takes a precious bath.

Hiding from the world, 11-year-old Dumisani tries to shut out his mother's anger.

For only a penny you can buy two sparrows,
Yet not one sparrow falls to the ground without your Father's consent -
Matthew 10 verse 29:

The words from the Bible that inspired the name, Sparrows, the Aids village in Florida, west of Joburg.

This is the second part of the story of Julia and Peggy, two women buffeted by hardship - extreme poverty, cold, abuse, rape and being abandoned by the fathers of their children.

In the first chapter we told of their years of hope, when they were young and had many admirers, their beauty, and, most importantly, their health.

When we met Julia and Peggy four months ago it was midwinter and the bitter cold added to their misery as they huddled in their draughty shacks.

Now, worse than all this: both women are seriously ill. Their memories are fading, neither can work, they are getting no care, and their families are falling apart.

And a remarkable friend who has entered their lives is convinced both are HIV-positive.

As they and their families hurtle towards a complete breakdown she persuades both to go to Sparrows Rainbow village, a Aids home and hospice.

There are millions of Julias and Peggies in our midst and this is their story, too.

JULIA'S STORY

Time of The Curse and the people of the night

Julia is topless. Her nipples lie flat against her chest. There are only wrinkles where the flesh of her breasts used to be.

Her daughter, 20-year-old Elizabeth, helps her pull off her skirt and her long, faded-white socks. Julia stands naked.

A burgundy cardigan is draped over her shoulders. Her narrow hips jut out forming a hollow cave between her legs. She steps into a tiny yellow bowl that a baby would hardly fit into and crouches down.

Her appearance now is dramatically different from the beauty with the opulent hips that her daughters remember.

The wind outside shakes the shack furiously. Julia trembles in her nakedness. It's the peak of winter and even clothes can't keep the chill away.

Elizabeth has warmed Julia's bath water over a small fire in the kitchen area.

Firewood is hard to come by and Julia's daughters have to walk long distances every other day, with a wheelbarrow and a saw borrowed from a neighbour.

They walk behind Julia's shack directly into the open veld behind it, along a well-worn path.

Kilometres away from their home in a squatter camp west of Johannesburg is a cluster of trees, where they usually collect the wood. Kilometres in the other direction is the comparatively wealthy area of Lawley One.

This is where small, brick, government houses stand. The roads are divided into streets and pavements. Everything is dusty.

There is no grass, but there is running water and electricity.

And on the same side of the road as Lawley One is Tshepomntwana, where the destitute live.

Here, by the shacks, are outhouses and heaps of rubbish thrown out and left to rot in the open.

Mangy dogs roll in the dust, and hens with their broods of chicks scratch around in the garbage.

Men sit outside their shacks in the sun, talking, watching everything.

Women walk around with their babies.

Few of the children go to school because few parents can afford to send them.

Julia's second child, 15-year-old Lydia, should be in high school but she can't afford the fees or the taxi fare to nearby Ennerdale. Lydia's younger brother, Peter, should be attending the Lawley Primary School but he is too hungry to go every day.

Instead he spends his days practising cartwheels in the dust and making up games with his friend.

"Everyone here is poor," Elizabeth says.

Back in Tshepomntwana Julia has been sleeping on the floor in the "kitchen", covered in blankets, trying to keep out the cold.

She has forsaken the steel frame of her bed, held up by bricks and a tin can, for the floor because the biggest holes in her shack are near her bed.

The wind that enters is so icy, her blankets can't keep her warm. Elizabeth has torn up old pages of a newspaper and fed them to the dying fire. Ashes from the previous fire rise in the air, and fall back down again sprinkling across Julia's blankets on the floor.

Soot and dirt have blackened the roof, as well as the old sheets and curtain that hang to divide the space into rooms.

Elizabeth is crying as she rocks her daughter, Mpho, who is snuggling her head into her body. The mother puts the toddler down, and then wipes her eyes.

From the floor, Julia's spiky hair sticks out from the bundle of blankets as she watches Elizabeth. She talks incessantly about the blasting wind.

Elizabeth thinks it was some time in 1995 that Julia went slightly crazy.

It could have been that she started suffering from HIV psychosis, a condition often seen in people in the advanced stages of the disease. It's in this stage that the virus attacks the brain cells.

It's Julia's belief that this was the time when the curse came and invaded her body, infected her chest, ate at her flesh and created a pain in her head.

She began to see the "people of the night".

They walked through the walls of her shack and, as she slept, they beat her body so that in the mornings, she would wake up with pains everywhere, cursing, shouting, chasing away the demons she saw.

She stopped her children - Elizabeth, Lydia, Christopher, and Peter - from eating, from sleeping, from performing bodily functions. She felt everything they did would bring the "people of the night" closer to attacking her.

She blamed her torture on the sangoma - the witchdoctor had cursed her.

The sicker she became, the less she could work. In the end, she stopped and there was no money for anything.

It's easier for the children to talk about it now.

But the constant shouting and bickering at the time finally made Elizabeth give in to her mother's wishes and she left home.

The girl remembers: "(Julia) said 'I don't like to stay with you. You must go look a place and stay alone.'

"She used to say 'You two girls must go, me I want to live only with Peter and Christopher'."

At the start of this year Elizabeth moved, and rented a room in a shack just across the fence from Julia. She pays R15 a month for rent.

Elizabeth remembers Julia always changing her mind, wanting to live only with her two sons one moment, then wanting to live with Lydia and Christopher and telling Elizabeth to keep Peter with her. When Elizabeth finally moved, Julia, in a moment of either regret or sanity, begged her not to leave.

"She said: 'Don't go. You are my child and must stay with me. I was joking.' But I said: 'No, I've found a place to stay'," Elizabeth recalls.

By then Elizabeth had already given birth to Mpho, who was two at the time.

Life continued just bearably for Julia. The curse might have been a fantasy, but then things turned.

The one thing that was real was Julia's rape.

Her children don't remember exactly when it happened, except that it was shortly before Easter.

Julia's ex-boyfriend is Majola. The children don't mention him by name. They don't say much about him, except that he lives behind Julia's shack.

They say he went to prison for killing his wife. When Majola was released, Julia didn't want to have anything to do with him. But he still wanted to be with her.

Later Lydia and Peter were to go to live with Elizabeth, while Christopher went to Julia's mother in Lawley One. But Peter and Lydia were still living with Julia at the time of the rape.

They had come back from watching television at a house at the end of Tshepomntwana. They like "Jet Li China movies", they say.

Their mother was sick at the time and stick-thin, just as she is now.

Majola was sitting outside Julia's shack when Peter told him his mother was

sick. Majola went away.

Later that night he came back, and raped Julia with Peter in the bed beside her.

"Peter was there. Two days he came and on the one day Peter was there," Julia recalls, with no emotion. She speaks as if she's talking about someone else.

She tried to persuade Majola to leave by telling him she was sick but it didn't work. He responded that she probably had Aids.

"I said 'If I have Aids why do you want to sleep with me?' He said if he gets sick then he'll take my pills and together we'll be sick," Julia says, sounding angrier about the suggestion that she had Aids than about the rape.

She never reported it - Elizabeth says Majola threatened to kill them if they did. Lydia is terrified of him. Whenever she sees him now, she hides.

After the rape, Elizabeth took Julia, Lydia and Peter to live with her.

But the neighbours complained about Julia's incessant talking. Elizabeth had to let her go back to her crumbling shack - to live alone without her beloved children.

It wasn't long after Julia's rape that Cora Bailey came into her life to offer her food, clothing, some dignity and hope.

Cora had first gone into the townships to look after sick and abused animals, but soon she realised that the people needed as much, if not more, help.

She came across Julia in her shack after Easter when someone in Lawley told her about a very ill woman. Cora began bringing donated food whenever she could.

Now Julia has become so attached to Cora that she has started pining for her if she doesn't visit for a few days.

A visit from Cora is enough to lift her out of her depression and, one day, Julia struts around because she's still thrilled about having seen Cora.

She's also pleased that, after having gone house to house begging, one of her neighbours has given her some food.

There's a pointy hat on her head, and she's wearing two jackets - the second one merely draped over her shoulders like a cape. Her skirt balloons as she walks and there's a green towel tucked into the side.

She sits down outside her shack and opens the container, then puts it aside in disgust.

"I was hungry so I went asking for pap. They gave some to me but I'm not going to eat it. I will throw it away. They play with me. They put chillies in it - I can't eat chillies," Julia says.

She puts the food down. She points to something Cora brought her which she could eat - baby food.

"I did eat it (the baby food). The bottle is here on the ground, it was nice," she says.

Julia looks forward to the visits. To her, Cora is her "Ouma" (grandmother), a benevolent force in her life. She says she is unhappy when she doesn't see Cora.

"I think of her as my ma. When I see her, I'm happy. When she doesn't come, my heart gets so sore," Julia says.

When the winter weather is at its worst, Cora doesn't sleep at night, sick with worry about Julia, alone in her shack filled with holes.

A fall of sparrows - Part 3

October 10, 2003

By Nalisha Kalideen

A fall of sparrows: The last flight

Part 3: We shall not forget Julia and Peggy, two ordinary women made extraordinary by their courage, love and spirit

For only a penny you can buy two sparrows,
Yet not one sparrow falls to the ground without your Father's consent -
Matthew 10 verse 29

The words from the Bible that inspired the name, Sparrows, the Aids village in Florida, west of Joburg. And so we come to the last journey of Julia and Peggy, the two sparrows of our chronicle. We spent many days over four months with them. Our intention was to piece together the story of their lives, the good and bad times, of their years of beauty and health and hope and love, and how this all changed with sickness, abuse, rape and the bitter cold of their shacks in Lawley, a settlement 30km to the west of Joburg.

We had intended to end our three-part series with their struggle to stay alive and care for the only joy in their lives - their children. But, of course, we couldn't write the script.

Our revised ending was to have been their journey to Sparrows Rainbow Village, an Aids hospice near Florida, and their reaction when they heard the results of their tests.

Again, we got the script wrong.

Julia and Peggy were far sicker than we realised, too far gone to be given Aids drugs, and even if they weren't, Sparrows wouldn't have been able to afford the treatment. But what they did get was love and care, and the chance to make their peace with their children. And perhaps they did.

The poet Alexander Pope, like Matthew in the Bible, wrote about the death of sparrows: Who sees with equal eye, as God of all,
A hero perish, or a sparrow fall.

Julia and Peggy were probably not heroes in the poet's sense, but they were to us. Their courage as they faced crushing odds, their spirit in a life of no hope and their love for their children in a hostile world, made these two ordinary women extraordinary.

We will remember them, as sparrows É and heroes. - Nalisha and Debbie

PEGGY'S STORY

Her name, too, will be put on the remembrance tree

The shack where Peggy once lay helplessly weak in bed seems very far away as she settles in at Sparrows.

She has been bad-tempered, even saying a number of times, in moments of helplessness and frustration, that she doesn't want her son Dumisani anymore.

On her first day at Sparrows, she's a lot calmer - but not more pleasant. She's sitting on the steps of the cluster she shares with the other mothers and their children. There's a blanket around her legs, and a green felt cap on her head that points comically upwards.

But there's nothing amusing about her expression. Peggy's face is screwed up, with angry wrinkles around her eyes and forehead. She has been finding fault with everything.

"Bread, bread, bread! There's only bread and eggs here."
Somehow because of her late arrival, there wasn't time to explain the workings of the place.

She's confused, and doesn't know about the meals, the clothes and blankets, the face towels and toothbrushes that are allocated to all the patients. She doesn't know who she should speak to about her TB tablets that went missing in her move.

Peggy is an intensely private person and doesn't want to draw attention to herself at Sparrows by asking either. Yet, at the same time, she suffers not in silence, but very audibly.

Later, Peggy is shown to the kitchen where lunch is being served. The steam rises from her plate, and Peggy picks tentatively at the chicken with her spoon.

"This food is not nice," she says. She'd prefer red meat.

Peggy is at Sparrows thanks to Cora Bailey, an animal lover who cares for the animals, and now also the destitute people, of Lawley, where Peggy lives. Cora brought her here.

In Sparrows' domed reception office, there is a hollowed-out tree, about 2m high by 1m, and on the bark are plaques inscribed with the name of each patient who has died there.

All the buildings look like pink igloos - it's a shape ideal to keep the rooms cool in summer and the sunlight that filters through the opening in the roof is said to help kill the TB.

Patients at Sparrows, a hospice and home for people with Aids run by Reverend Corine McClintock, are taken care of for free, they are given medication, three meals a day, clothing, counselling and social worker Michelle Brown arranges for them to receive disability grants.

There is an in-patient hospice where patients get 24-hour nursing care and cluster homes where the healthier patients live.

Peggy's 11-year-old son, Dumisani, who is living with her at the hospice, is being destructive. Maybe not deliberately, but through curiosity.

He has blown up a kettle after putting the plug in water and switching it on. He has stuffed things in the toaster, switched it on and damaged it. And, sometimes, he has hit his mother.

Peggy can't control him and sometimes cries because she doesn't know what to do. She says again that she doesn't want him.

Social worker Michelle is worried about the boy's behaviour. "We need to find a better place for him, we need to separate him from his mother," she says.

"He can't stay and watch his mother die."

That afternoon, Dumisani is moved to a cluster just for children. But he moves back to Peggy's cluster and stops attending the crèche during the day.

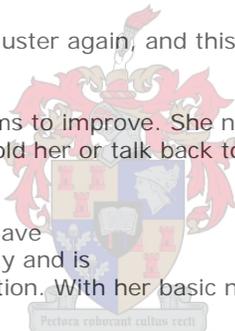
"He seems to be travelling between the two places, causing chaos," says Michelle. "I suppose he's going to be the picture of what's going to happen to his generation of HIV-negative children."

Peggy can say exactly when her son's behaviour changed. "Since I was sick," she says. "Before I'd shout at him and he'd be good and would listen but when I started to get sick, he stopped. I don't know what's happening to him."

Dumisani is moved into the children's cluster again, and this time he stays there.

Slowly, his relationship with Peggy seems to improve. She no longer complains about him and he doesn't scold her or talk back to her.

Michelle explains: "The circumstances have changed. Here she is fed six meals a day and is being cared for and is receiving medication. With her basic needs being met, she can be a good mother."



And with Dumisani living away from her, with other children to play with, he also "gets on her nerves much less".

The social worker says Dumisani will need a male authority figure and supervision as he approaches his teenage years. And she tells Peggy her concerns, asking her to decide what will happen to Dumisani if she dies.

Immediately, Peggy decides he should stay with her younger brother, Washington, with whom she grew up in Mafikeng.

Peggy wants to go and visit her brother for the weekend - to tell him where she is. Michelle advises her to discuss Dumisani's future with Washington.

Peggy is worried about her payments for her funeral policy, which she could lose if she does not pay for more than three months. Michelle assures her that Sparrows will give her money to catch up.

Peggy's worry about the policy is really worry about her son. When she dies, the family will get R3 000, and it's that money that she's afraid of losing.

"When I'm not in life, he's going to suffer," she says.

It's about this time that Peggy meets Julia for the first time, even though they have spent years living just kilometres from each other.

Ill and in pain, watching as their families struggled to cope, they have each believed that they were the only one. But they aren't. One afternoon, Peggy sees Julia sitting outside in the sun as she is on her way to the kitchen for lunch. Peggy stops and starts talking to Julia, but the encounter is brief.

Julia tells Peggy that she's from Lawley but nothing more. She doesn't even mention her children whom she usually talks to everyone about. Peggy says she's also from Lawley, but doesn't mention Dumisani.

Julia has started smoking and Peggy later talks about her habit in a disapproving tone.

They become acquaintances and nothing more.

Peggy's brother Washington immediately steps in to help when he hears of his sister's illness.

He's only 28 years old, but he agrees to take on the responsibility of looking after Dumisani. He leaves his on-off girlfriend from Soweto and, with his 2-year-old daughter, moves into Peggy's shack in Lawley.

Peggy's relationship with Washington's girlfriend has always been strained. She remembers a time when she was ill and staying with her brother, the girl refused to help take care of her or even cook for her.

So Peggy is thrilled that he's left her and decided to look after Dumisani, her 18-year-old niece Letang, and Letang's son, 2-year-old Tony.

Washington extends Peggy's shack and adds on an extra room and with the income he receives from fixing cellphones and appliances he supports them. He's also strict and insists that, from next year, Letang will go back to school.

When Peggy starts receiving her disability grant, she gives half of the money to Washington so he can buy goods to hawk.

She's all smiles, and filled with relief now that she knows her loved ones will be taken care of.

"I'm happy. Things are better now. I'm not feeling like before," she says, giving a thumbs-up.

She says she still hasn't received the results of her HIV test. "I didn't have time to get my results. But I can see that I'm positive.

"There's nothing I can do about it. The people here have it too. What must I do? Take my heart out because I have Aids?" Her brother is accepting too. When she told him, on a visit to Lawley, he was supportive of her.

"I accept it because Peggy is my sister. There is nothing we can do," Washington says.

Peggy seems to have been getting better, and has been making trips to Lawley by herself.

But after a month, she suddenly takes ill and has to be moved from the cluster home to the hospice. She is placed on oxygen and Dumisani goes to visit her, in tears.

"He came to see me and was just crying. He was scared," Peggy says.

But two days later, she is taken for a check up at Helen Joseph Hospital.

She talks about her time in the hospice, without a hint of fear for her health.

"My bones felt very sore and you know me, when I'm sick I cry. I was crying too," Peggy says laughing.

But later, after she returns from her visit to the hospital she feels tired again and complains about the pain she feels in her bones.

Peggy says her CD4 count, which is the measure of a person's immunity, is five. In a healthy person, it's usually 1 000. It seems like life is slowly slipping away from her.

Peggy is admitted to the hospice two weeks after Julia's death. She doesn't get an individual room, but is instead moved into the conference room with two other women.

It's the room where the staff have their morning meetings. But the long conference table has been moved out to accommodate the patients.

She can't breathe and has been crying. She complains about being constipated and says there is a terrible pain in her stomach. The nurses hook her onto an oxygen tank to help her breathe.

The next day, Peggy has a fit. The nurse hears her screaming for her son: "Dumisani don't leave me!. Dumisani don't leave me!" The next morning, Peggy is moved to a private room. She slips in and out of consciousness.

She lies on her back, her hands folded across her chest, and she whimpers occasionally, her fingers fluttering slightly to show her pain.

Now her face doesn't contort in pain as it once did. It's free of the creases. She cannot speak. Her breathing is difficult, her mouth is slightly open, and there is mucous around it.

It's a warm day, but Peggy's hands and arms are freezing. Her face, in contrast, is warm. It's as if she is slipping away slowly, starting from her hands.

Dumisani is brought in to say goodbye. Before, she begged him not to leave her, but it's she who leaves him.

His sparrow has fallen.

OVERALL																					
Total no. of reports	Negative						Positive						Neutral								
83	32						39						12								
Single source reports	G/	A/	P/	S/	AD/	DA/	PH	G/	A/	P/	S/	AD/	DA/	PH	G/	A/	P/	S/	AD/	DA/	PH
46	10	2	1		1	1		3	2	6	8		1	1			3	1	3		2
	15						28						10								
CAPE ARGUS																					
Total no. of reports	Negative						Positive						Neutral								
16	8						8						0								
Single source reports	G/	A/	P/	S/	AD/	DA/	PH	G/	A/	P/	S/	AD/	DA/	PH	G/	A/	P/	S/	AD/	DA/	PH
5	3		1							1											
	4						1						0								
CAPE TIMES																					
Total no. of reports	Negative						Positive						Neutral								
21	10						8						3								
Single source reports	G/	A/	P/	S/	AD/	DA/	PH	G/	A/	P/	S/	AD/	DA/	PH	G/	A/	P/	S/	AD/	DA/	PH
16	3	2						2		1	4		1				1	1		1	
	5						8						3								
DIE BURGER																					
Total no. of reports	Negative						Positive						Neutral								
46	14						23						9								
Single source reports	G/	A/	P/	S/	AD/	DA/	PH	G/	A/	P/	S/	AD/	DA/	PH	G/	A/	P/	S/	AD/	DA/	PH
25	4				1	1		1	2	4	4			1			3		2		2
	6						12						7								

APPENDIX Q: Figure 6: Number of single sources used overall and per newspaper with direction denoted