

## **Narrating from the body: Health and the state of our nation**

Kerry Cullinan delivered a paper at the Narrative Journalism Conference hosted by the Nieman Foundation and the Wits Journalism School.

I want to start with a lament about how health is viewed by the media establishment. Traditionally, health has been seen as a junior, female beat in South African journalism.

Not only is health seen as being a women's beat, but many newspapers, radio stations and TV channels have a particular view of health (excluding AIDS) as "women's stuff" that focuses on dieting, vitamins, natural remedies, alternative therapies and how to deal with "family illnesses".

Yet in newspaper and magazine readership surveys, both men and women consistently indicate their interest in health issues. In addition, "Men's Health" magazine, which was launched in 1997, claims that it has 292 000 regular monthly readers, 44% earning over R12 000 a month.<sup>1</sup>

Today, I want to challenge you to look at health differently. I hope to convince you that health offers opportunities to connect with readers of both genders, all races and most religions. In addition, I hope to show how health can be used as a highly effective tool to analyse contemporary South Africa and that narrative journalism often provides an excellent method for telling health stories.

### **What is health?**

Dictionaries define health as a state of physical and mental wellbeing and the condition of being disease free. We, in the media, have tended to see health either in a narrowly medical way, focusing almost exclusively on physical conditions and diseases or by looking at "new age" alternative therapies.

Mental health tends to be focused on motivational issues in terms of how our attitude affects our performance. There is still a great deal of stereotyping of people with mental illnesses. There is little conscious acknowledgement that "social fabric" issues such as rape and alcohol abuse are health issues.

We seldom make connections between levels of service provision and health. But whether communities have access to clean water, decent sanitation and housing is directly linked to their wellbeing. In 2000, for example, there was a serious cholera outbreak in northern KwaZulu-Natal. This was generally reported in the media in narrowest of terms as a medical emergency. It later emerged that the epidemic was directly related to the introduction of pre-paid water meters, the continual malfunctioning of these pre-paid water meters and waits of up to six weeks for the municipal staff to fix broken taps. These drove many people to get water from the uMhlathuze River which was identified as the original source of the cholera bacteria. Lack of proper sanitation in

Ngwelezane and limited clean running water meant that cholera bacteria, which is spread through contaminated water and food, was able to spread rapidly from person to person.<sup>2</sup>

In 2002, the country's first HIV/AIDS household survey was conducted by the HSRC-Nelson Mandela Foundation. This found that people living in informal settlements were the most vulnerable to HIV infection. Although those living in rural areas were a lot poorer, it was the instability and transitional nature of informal settlements, where bonds of community and family are not that tight, that made people more likely to engage in risky sexual behaviour.

Last year, a study of eight villages within a 20km radius in Sekhukhuneland in Limpopo by Wits University's Rural AIDS and Development Action Research unit found a variation in HIV prevalence from 1%-46%. In trying to understand what made one area more vulnerable to HIV than another, researchers concluded that communities were more at risk if their village was on a main road, near to the local mine or main trading area. Men were particularly at risk if they lived near bars or in villages with a high proportion of sex workers. Income and educational levels were found to be irrelevant.

So living conditions and location are closely tied with health and when we try to capture the texture of people's everyday lives, finding out where and how they live can tell us a great deal about the health risks they might face.

### **Health as political analysis**

Worldwide, health indicators are acknowledged as an accurate way of measuring how developed a country is. Statistics about how we are born, live and die speak volumes about a society. The infant mortality rate (how many babies die per 1000 live births before the age of one), under five mortality rate, maternal mortality rate (how many women die during childbirth), life expectancy and causes of death are very important indicators of the health of a nation.

Health indicators will tell you far more than any politician would ever dare to. They can provide direct insight into the quality of everyday life of ordinary South Africans. This is the real "body politic"!

I believe that our nation's vital statistics open the doors to thousands of narrative possibilities as well as offering a powerful and direct way of assessing how well we as a nation are progressing, bypassing all party political rhetoric.

So what do our health statistics say about us?

For a start, more children under five are dying now than they were under the apartheid regime. In 1975, the year before Hector Peterson and hundreds of other Soweto school children were shot dead by apartheid's police, for every 1000 children born, 89 would be dead by their 5<sup>th</sup> birthday.

By 1998, the new democratic government had reduced this to 59 deaths by the age of five out of every 1000 children born. But in 2000, 95 children per 1000 born were dead before they turned five.<sup>3</sup>

In addition, we have a completely abnormal adult death pattern for a developing country such as ours. The Bureau for Market Research at Unisa tells us that three times the number of women aged between 20 and 30 and double the number of men aged 30 to 40 are dying than should be for a country such as ours.

If any politicians were to stand up in Parliament and say that small children and adults under 40 are worse off now than prior to 1994, they would probably be condemned as being anti-patriotic racists. Some of the AIDS denialists, who dispute that HIV exists but love to boast of their cosy relationship with our President, have chosen to cast doubt upon these statistics. But the Medical Research Council has been counting bodies in mortuaries. While there are still disputes about the causes of death, no one can hide the bodies or disguise how young those corpses are.

Outside of the context of the AIDS epidemic, these figures would be a shocking indictment on our democratic government. But for those of us who both accept that HIV causes AIDS and that the ANC government has made genuine progress in improving the living conditions of millions of South Africa, these statistics can only be attributed to the AIDS epidemic, which may prove to be a more formidable enemy than apartheid.

By 2002, AIDS was responsible for 40% of dead adults. The Actuarial Society of Southern Africa predicts that 47% of deaths this year will be AIDS-related. AIDS is overwhelming communities countrywide and the government's HIV/AIDS comprehensive treatment and care plan (which includes providing antiretroviral drugs to those who need them) is being rolled out far too slowly and without proper leadership or management.

While AIDS is by far our biggest killer, almost as many people (37% in 2000) are being killed by a combination of chronic diseases such as heart attacks, strokes and hypertension. These chronic conditions are almost all directly associated with poor diet, lack of exercise, smoking, alcohol abuse and being overweight – all indications of a modern, westernised lifestyle.

Chronic disease experts also blame our worsening health and thickening waistbands on the rapid expansion of fast food outlets in the country after 1994. Prosperity has come to mean being able to offer your visitor a carbonated soft drink, to give your children white bread for school or to go to KFC or McDonalds as a treat. The links between success and consumption are cemented by the advertisements that we run, as producers of fizzy drinks, fast foods, alcohol and cigarettes seek to colonise new markets in the developing world.

Aside from the killer combinations of infectious and chronic diseases, we are a violent nation. A Cuban doctor working in a hospital in Kimberley, which has one of the highest

incidences of assault in the country, told me that stabbing one another is South Africa's "national sport".

Homicide and violence is our second biggest killer overall (7.5%). About one in five teenagers will die of injuries, the vast majority (61%) of which were deliberately inflicted on them by other people. Road accidents (21%) and suicide (10%) are the other main violent killers of our teens. Very often those who suffer violent deaths are young men. Very often excessive alcohol abuse is a factor in homicides and accidents. We assume that the "born free" generation is better off than their parents, but these health statistics show that young people are under intense pressure.

We are also still a nation divided. Health indicators demonstrate perfectly President Thabo Mbeki's "two economies" thesis. Take a 2002 youth survey of school children in Grades 8-11. Over one in five African and coloured youth were either underweight or stunted. In contrast, one in three Indian and white teens were either overweight or obese.<sup>4</sup>

The kind of healthcare you can get is also determined by where you live and what you earn. Limpopo is so short of doctors that a woman giving birth in a public facility will have a one in 10 chance of ever being seen by a doctor.

But a woman giving birth in a private health facility in a major urban area will have a highly medicalised birth, attended to by specialists and an almost 40% chance of a Caesarian (against an international norm of up to 15%). What does this mean? Surely not that women in Johannesburg's northern suburbs have abnormally small pelvises?

### **The special case of HIV/AIDS**

No other epidemic in humanity's history has killed as many people or had as much impact. Other epidemics tend to kill the weakest: the very young and the very old. AIDS kills young people in the prime of life.

Because the epidemic is so massive and so all-consuming, it has become a microcosm of all post-apartheid South Africa's challenges and weaknesses. Some of these include:

- Gender imbalances, including violence against women and children;
- Economic imbalances, whereby the wealthy were able to get access to ARVs while the poor died of AIDS-related illnesses;
- Political weaknesses, whereby our President has been able to indulge in pseudo-science and very few leaders in the ANC have been prepared to challenge him because the system of proportional representation means politicians are accountable to their party rather than their constituencies.
- Government's confusion about how to deal with protests from civil society
- Tensions between tradition (in this case, traditional medicines) and "westernisation" (medical science).
- Racial divisions, whereby the views of the scientific community – dominated by white males – were discounted by the new black government.

- Problems with service delivery, particularly in rural areas, as our old and overburdened health system struggles to deal with the huge influx of AIDS patients
- Skills shortages.

The democratic government's handling of HIV/AIDS has been disastrous. As a result, its first ever challenge from civil society came from the Treatment Action Campaign, which demanded affordable healthcare for people living with HIV. For the first time, the ANC-led government lost the moral high ground when the Constitutional Court compelled it to provide nevirapine to pregnant HIV positive women.

We are the only country in the world that is discussing nutrition as an alternative to ARVS. But the current struggle between the Health Minister and the AIDS community over her insistence that nutrition is an alternative the drugs is not the isolated battle of a lunatic. It should rather be seen in the context of Nepad, and the hunger to reclaim past "indigenous knowledge systems". The alignment of certain sectors of traditional healers behind vitamin peddling Dr Matthias Rath is part of the same ideological battle.

However, HIV/AIDS has also brought with it opportunities that we have not fully appreciated. It has brought a new openness about sex, spotlighting harmful practices that have been unchallenged for decades. It has brought a large influx of donor money which can be used to strengthen the entire health system. It has invigorated our scientific community and created opportunities for unique partnerships between organisations that normally would not have much in common.

But we in the media are failing to join the dots and to see AIDS in context. In addition, as AIDS affects virtually ever part of our society it should be a focus of all reporters, from finance to sport. Government has reorganised itself into clusters of similar ministeries but we are still working in silos.

There is also very little understanding in newsrooms about accepted scientific practices, including the importance of evidence-based medicine and peer-reviewed articles. As a result, there has been much confusion within media institutions about how to deal with the AIDS denialists. Ideology has become confused with science. In our desire to appear balanced, we have elevated notions that have little scientific standing.

### **What about narrative journalism?**

I have tried to show that health indicators are a very useful way of unpacking political rhetoric and showing how people in South Africa are living, 11 years after political liberation.

But some of our statistics and projections, particularly those relating to HIV and AIDS, are so overwhelming that they can cause instant denial. When I first read loveLife's projection that half the teenagers I knew in 2000 could become infected with HIV in the

next decade, my immediate response was: “Rubbish”. I could not digest the figure because it was too big and too alarming.

So statistics, aside from being hard to digest, are often too alarming or too abstract to sink in. How do we make these figures more palatable so that we can tell the stories that are happening in South Africa? Is this where narrative journalism comes in?

There is little tradition of narrative journalism in South Africa. Most of us are schooled in news reporting. This means we are used to telling stories backwards. In very poor story-telling style, we take out any suspense by revealing the punchline first, followed immediately the most important facts. In print, our stories usually trail off without any decent conclusion because we know that the sub-editors will hack off the bottom paragraphs.

We diligently rattle off the “who”, “what”, “where” and “when” parts, but often we neglect to delve properly into the “why” and “how”. How many times have you covered something so compelling, yet by the time your story gets out there it is as dry as a GCIS press release? Much of our news reporting is boring and formulaic because we don’t pay enough attention to the actual crafting of the story, set only on cramming in as many “facts, facts, facts” as possible. This devotion to fact above feeling also means that essential detail is usually viewed as optional colour and is edited away.

But what is narrative journalism? I used to think a “human interest” story could pass as narrative journalism. But if this is the case, then the tabloids do human interest pretty well. But the tabloids focus either on celebrities or people caught in extreme situations. Either way, this simply makes our readers into voyeurs. I am not saying that we ignore the exceptional or the extraordinary, but I think that we also need to recognise the value of focusing on the lives of the ostensibly ordinary.

We no longer live in an age where we need to go out do battle with wild animals in order to bring home supper. Modern heroic tales are often those that involve ordinary individuals’ struggles with disease and disability or simply with the difficulties of keeping afloat when poverty threatens to drown them. During this struggle for a better life, they often discover an inner strength and heroic qualities that might not have come out otherwise. We need to write stories about these people that will strike a chord with the average reader, moving them from “ag shame” or “ag sies” to “yebo”!

### **Narrative opportunities and possibilities**

Journalist Ida Jooste, while on a fellowship with the Wits Journalism Programme in partnership with the Perinatal HIV/AIDS Research Unit, did some research on how receptive people in a poor community in Durban, were to HIV/AIDS stories. Interestingly – and surprisingly for those of us used to be told by news editors that the public is “tired” of AIDS stories – Jooste found that the Cato Manor residents had “an overwhelming need ... for more HIV news, particularly news about ‘ordinary people’.”<sup>5</sup>

So how do we make stories about everyday heroes and small-time villains compelling, given that these stories will be competing for very limited space with the big political and sensational stories of the moment?

US journalist-turned-academic Walt Harrington talks not about narrative but “intimate journalism”. This he describes as “news you can feel” and aims to “describe and evoke how people live and what they value”. According to Harrington, “The eternal verities of love, hate, fear, ambition, dedication, compassion are still our bread and butter. Always remember: Scene detail and narrative bring a story to life, while theme and meaning imbue it with a soul.”<sup>6</sup>

Harrington offers a few basic techniques to achieve journalistic intimacy:

- Thinking, reporting and writing in scenes
- Capturing a narrator’s voice and/ or writing the story from the point of view of one or several subjects
- Gathering telling details from our subjects’ lives that evoke the “tone” of that life. (engaging all five senses)
- Gathering real-life dialogue.
- Gathering “interior” monologue (not just facts but the meaning these facts have for our subjects).
- Reporting to establish a timeline that allows us to write a narrative article that at its beginning posits a problem, dilemma or tension that will be resolved or relieved by the end the story, with a resultant change in our main subject or subjects.
- Immersing ourselves temporarily in the lives of subjects so they become relaxed in our presence
- Gathering physical details of places and people at specific points in conversations or scenes so they can be used at exactly those points in our story.
- Always being aware that no matter how artful our stories may be, how specific they are to the lives of our subjects, they are primarily meant to enlighten, caution, criticise or inspire, always resonate, in the lives of readers.

These are invaluable pointers. When I hold up some of my own stories against these, I become unsure about whether I have ever succeeded in going beyond “human interest” to true intimate journalism. Before I produce a litany of excuses about how difficult it is to introduce intimate or narrative journalism into our fact-hungry, space-starved media environment, I thought I would look at a few of my efforts and offer some of my experiences and self-criticisms.

I have focussed on two stories aimed at giving readers insight into the personal costs of HIV/AIDS through the experiences of a single individual or family.

*Love in the time of AIDS (Sunday Times, December 1 2002)*

World AIDS Day offers a rare opportunity to write a story about someone with HIV/AIDS, knowing that there will be space. I decided that I wanted to write about what

the virus can do to a person's intimate relationship. Often testing HIV positive is the first shocking confirmation a person has that their partner has been unfaithful to them. Women usually get tested before their male partners as they are strongly compelled to be tested when pregnant. I was looking for a woman who had discovered her HIV status and this discovery had fundamentally changed her relationship.

I searched for three months before meeting Bongi. She had never told her story to anyone before and it was very painful for her. For five days, she came to my office and we spoke for 3-4 hours. I tried to recapture the early days of being in love, then the ugliness that accompanied her disclosure that she was HIV positive. On the fourth day, I read her bits of the draft I had formulated. Sometimes the written word can be shocking to a person. She was subdued for a while after I had read my draft and checked some of the detail with her. It was only then that she dropped her bombshell: that Elliot had known long before she had tested HIV positive that he was HIV positive.

*AIDS entered their lives like an intruder, tearing into their already fragile marriage and turning Elliot into a hostile stranger.*

*"It took me about two weeks before I told him. I started to talk, asking if he knew anything about AIDS."*

*Elliot's response was aggressive: "Don't talk to me about AIDS. Do I look like a person with AIDS? As from today, you must never talk about AIDS in my house," he threatened.*

*"When he said this he looked like a man who was about to slap me, so I kept quiet. But this thing was eating me inside, making me thinner and thinner. I knew I had to tell him, so after a while I just said to him 'I know you don't want me to talk about AIDS. Well, I don't want to talk about AIDS but I need to talk about myself. I am HIV positive'."*

*Elliot remained silent. Then he got up, left the room, returning with a glass of water. "All this time I thought you were my wife," he told Bongi coldly. "But now I see you just look like all the other bitches. If I had known I would have had this problem, I would never have looked at you."*

*Then he set out his ground rules. "You must never tell anyone about this. You must not visit anyone and no one must visit you."*

It was only by spending a lot of time with Bongi that she was able to acknowledge – even to herself – what had hurt her the most; that Elliot had turned into a violent monster that blamed her for bringing HIV into their home when all along he had known his HIV status. She had been so hurt by his denial that it was difficult for her to admit this even to herself, let alone to me. It was not until we had spent some time together that she was able to reflect on this and how much pain it caused her. This taught me that there is no shortcut to getting the important detail, especially when it is this painful. People can only tell you when they are ready.

I never interviewed Bonggi in her home as she was unsure about how her family would react to her going public with her story. I always regret this as it made the story about Bonggi's past in a way that was removed from her present. I also think at times my narrator's voice stands in the way of her own inner thoughts coming through.

*The loneliness of Zwe (Sunday Times, September 12 2004)*

Zwe, Zamo and Ndumiso are a family of three brothers who live alone. They have witnessed their older sister, mother and her boyfriend dying. Zwe, who was 15 when I interviewed him, had been caring for his 11 and 7-year-old brothers for 18 months.

*"Phaa, phaa, phaaa". The boys kick a flattish soccer ball around on the narrow strip of orange dust in front of the house. Each time Zwe dribbles past one of the others, a giggle of delight bursts from him – brief moments of pleasure in his overburdened young life. Zamo, however, doesn't stick around. A bit of a comic, who often communicates with exaggerated expressions, he roams the township most of the weekend. "Just visiting", he says vaguely before disappearing.*

*Gone for six or seven hours at a time, Zamo's life seems to be slightly out of step with that of his brothers. He cooks and washes for himself, too old for Zwe's care but too young to care successfully for himself.*

*Zamo says friends visit him, but he doesn't know if they realise he doesn't have parents.*

*"We never talk about it," he says.*

*Zwe does not talk about their situation either: "I don't tell anyone we are living alone. There is no reason."*

*He also does not accept food from the school feeding scheme although this is how the two younger boys get lunch. He won't explain why he boycotts the feeding scheme, but it is clear that the quiet boy is intent on preserving a public façade of normality in his little home and perhaps accepting a handout would be an acknowledgement that all is not well with the Madlalas.*

This story relied almost entirely on observation. I wanted to show what it is like when children are running a household. But there were other reasons. There was a language barrier between us, and Zwe by his own admission did not relate well to adults. When around adults he became very withdrawn and subservient and tried not to draw attention to himself. In addition, the only interview I had with him was mediated by a fieldworker from an NGO that channelled food and clothing to Zwe's family. Photographer Katherine Muick and I simply camped out at the family home for two days and watched every exchange and detail. The boys got used to us after a while and ignored us. We were able to watch them preparing meals, preparing for school and just hanging out with friends. I had virtually no access to Zwe's "inner monologue" but there was plenty of dialogue between them to draw conclusions from.

By touching on these stories, I wanted to share very briefly some of the opportunities and pitfalls I have experienced while trying to write intimately about AIDS. I am far from succeeding, but the few lessons I have learnt are as follows:

- Long, rambling conversations work better than formal interviews. In interviews, subjects are very self-conscious. So many times once I have stopped writing and put away my notebook (ie started behaving like a normal human being) the subject relaxes and becomes more him/herself than an “interviewee”. Often in this “down time”, a person will make their most important observations and comments.
- Never expect your subject to be able to understand what you are looking for. Ask questions about all kinds of things. Objects that you come across in their homes, work place, car etc are often a start. These often reveal stories that would never have come to light anyway.
- Nothing can take the place of spending time with a person in their home environment and seeing them with family and friends.
- Taking photographs helps with the writing afterwards as there is usually too much to try to absorb at the time.
- While it is fine to have an idea of what you want, it is important to be flexible. Things don’t often turn out the way you expect that they will and approaching a person or story with too many preconceived ideas can blind you to realities that are often even more interesting than expected.
- Prioritise and simplify. Sometimes I have done so much research that I am reluctant to leave out any of the information. But then my story ends up with a blizzard of fact-confetti obscuring the narrative.
- It is important to try to explain to your editor/ news editor/ sub-editor what you are trying to achieve. Unless they have some understanding, your lovingly crafted story is in danger of being savaged by the news hounds.

### **Narrative opportunities and possibilities**

Despite the limitations of space, time and the imagination in many of our media institutions, narrative journalism needs to find a voice if we are to captivate our audiences and engage them on deeper levels and offer them something beyond the transitory and the superficial.

I suspect it is mostly up to ordinary journalists to take the initiative. Time is the enemy of media institutions but an essential component of narrative journalism. If you ask your editor if you can follow a subject over six months you are likely to be asked if you have lost your mind. But it is possible to develop a story over weeks and even months, by only devoting one afternoon a week to it. This is particularly possible with health stories involving either a person’s demise or recovery, both of can be slow. Following people over a long period of time can be very rewarding and informative.

But then comes the telling and that often means that all this time spent observing goes into a 1000-word story or a radio documentary that’s over in minutes. There is little tradition of running a series in newspapers, although the series, “A fall of sparrows”, shows how powerful this can be.

In 1996, Roy Peter Clark from the Poynter Institute in the US, wrote a 30 000-word series called “Three little words”. Clark focused on a family struggling with AIDS and broke their experiences down into chapters of 800-1000 words each. These were run every day in the St Petersburg Times for 29 consecutive days. Part of the motivation, says Clark, was to “build readership and get people to return to the habit of reading the paper every day”.<sup>7</sup>

It is unlikely that any local newspaper would run such long series. But it is possible that longer serialised stories might work with online editions. Journalists could write develop their stories over a number of days, rather like a web diary or a more conscious form of blogging.

At the very least, we can employ narrative techniques in our run-of-the-mill features and news stories to bring these to life.

In concluding, I would like to return to HIV/AIDS. Although the epidemic is tearing through our communities, destroying families and the already tattered fabric of many communities, there is no sense of urgency in the South African media. The leadership vacuum in HIV/AIDS is undermining HIV prevention efforts and jeopardising the 85% of uninfected South Africans. We have a role to play in bringing home to our audiences what is happening in our country. Why aren't we doing it? (Delivered June 2005)

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<sup>1</sup> See [www.menshealthsa.co.za](http://www.menshealthsa.co.za)

<sup>2</sup> The Cholera Outbreak: A 2000-2002 case study of the source of the outbreak in the Madlebe Tribal Authority areas, uThungulu Region, KwaZulu-Natal available at <ftp://ftp.hst.org.za/pubs/research/cholera.pdf>

<sup>3</sup> Under otherwise identified, all health statistics in this section are taken from South African Health Review 2003/4, Health Systems Trust

<sup>4</sup> The National Youth Risk Behaviour Survey [www.mrc.ac.za/healthpromotion/healthpromotion.htm](http://www.mrc.ac.za/healthpromotion/healthpromotion.htm)

<sup>5</sup> See <http://journalism.co.za/images/upload/Fellow-paperIda.doc>

<sup>6</sup> Harrington, W (1997) *Intimate journalism: The art and craft of reporting everyday life*. Thousand Oaks: Sage

<sup>7</sup> See interview with Clark at <http://www.asne.org/kiosk/editor/december/clark.htm>