

# *Body of evidence: The case for health narrative*

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## ***Introduction***

As journalists, we are supposed to tell the stories of our time. Some of those stories we tell very well, others we do to death but many we simply ignore.

I am going to try to persuade you today that using “health” (and taking a very wide definition of that word) provides an entry to telling both the very big stories of our time as well as the “small”, personal ones that humanise our media.

Over the past few years, with the shrinking of resources in the media, some of the press in particular (but SABC TV and radio too) have started to resemble “fast-news” franchises, similar to fast food places where, no matter whether you’re in Pholokwane or Cape Town, the place looks the same and the food is identical sweetened cardboard. I can read The Star in the morning, catch a plane to Cape Town or Durban and read the Argus or the Daily News and have a sense of déjà vu. Same old, same old.

Aside from syndication, there seems also to have been the death of imagination. Most of our stories are reactive rather than based on fresh research, where an idea has been developed in a newsroom over time and then brought to a conclusion.

The mainstream press in particular seems to be far too conscious of the tabloids, vacillating between vacuous celebrity gossip and sex scandals, and hard news. There are few features, many imported, and pages of opinion – the easiest kind of reporting to do.

The voices and experiences of ordinary people – not rapists, frauds, politicians or celebrities – seem to have virtually disappeared from our media reports, particularly the mainstream press.

I am appealing for us to recapture the stories of ordinary South Africans – people that our readers, listeners and viewers can empathise and identify with, not watch with voyeuristic but detached fascination.

So today, I am going to try to make a case for the ordinary. And to do that, I am going to go back to basics, and to what we have in common with one another: Bodies, the basic physical unit of a human being and Health, perhaps one of the lowest common denominators between humans, and a subject that every human being has an interest in (if in doubt, check out your readership surveys).

I like to think that the body never lies. But of course it does. A healthy-looking person can fall down dead from a heart attack. An immaculate exterior can conceal an interior that is morally or intellectually bankrupt.

But mostly, the things we try to conceal even from ourselves emerge through our bodies. Stress, substance abuse, insomnia... become etched in our faces and bodies.

Not long ago, I spoke to a woman who had been very sick. She had peripheral neuropathy (does anyone know what that is?) and had lost a lot of weight. She lived in a Durban township.

“My neighbours would all come to visit me. They pretended that they wanted to see how I was. But I could hear them saying to each other, as they went out, ‘See, that is what a person with AIDS looks like’,” she told me.

She was about to start antiretroviral drugs. At the clinic where I met her, it was the rule that before a patient could get ARVs, they had to have disclosed their HIV status to someone close to them.

“Even if you don’t disclose that you have HIV,” said the trainer, “your bodies will disclose for you.”

Her body already had. And although her neighbours probably didn’t know the medical term “peripheral neuropathy”, they had seen and heard enough about people with AIDS to know that her symptoms were AIDS-related.

The body is a great place to start for stories. It is the site of many dramas. Perhaps not courtroom dramas that can make or break leaders, but life-and-death dramas of individuals. So how do we start writing about the body in an interesting way? can we really tell the big stories of the day from the health perspective?

I am going to start with an example, “Mrs Kelly’s Monster” written by Jon Franklin, who was a science writer for Baltimore’s Evening Sun at the time. It’s a thriller about a surgeon’s race to extract a monstrous growth from a woman’s brain as her vital signs get weaker and weaker, punctuated by the “pop, pop, pop” of the heart monitor.

[Extract from Mrs Kelly’s Monster]

Franklin, who won a Pulitzer Prize for the story, says he was “interested in science and technology as it was being lived by real people”.

People like Mrs Kelly face such operations every day. Shouldn’t we be writing about their experiences?

But who are the South African Mrs Kelly's? What can their bodies, and the illnesses and traumas they endure, tell us about our country, its history and how the not-so-new South Africa is unfolding?

Unfortunately, as a developing country with a history of having both the best of the developed world reserved for the white population and the worst forced on the rest of the population, we now have both the disease profiles of really rich and really poor countries.

### ***Infectious diseases***

No country can avoid an epidemic caused by an infectious disease, but a country with resources and a strong and well developed health system can react fast and contain and control epidemics.

### **Tuberculosis**

We have an epidemic of tuberculosis, a bacterium that is passed through the air. In 2004, there were almost a quarter of a million new cases of TB in the country. Only half of those patients were cured. All of us in the room (bar probably those from Europe and the US) have the TB bacteria in our bodies and could develop TB if our immune systems get weak.

TB can be cured after 6 months of treatment. But we are unable to get that right. Patients don't come back for their medication. We can't find them. They infect others. More and more people are getting multi-drug resistant TB. If someone with MDR TB sneezes on you in the taxi, you can get the MDR strain of TB too even if you have never had TB before.

So where's the story? Last week's New York Times announces with alarm that MDR TB in the US is growing and there are now 200 XXX cases. One TB hospital in one province had 728 MDR TB cases last year. Now they also have multi-multi drug resistant TB. And if they can't cure a patient, they have to discharge them ... to breathe on others in the taxis, shops and schools. Imagine following one infectious MDR TB patient through their normal day.

### **HIV/AIDS**

So we've messed up with TB treatment, and that is only for six months. Yet we think we can address HIV and AIDS with life-long antiretroviral therapy.

By mid-2004, AIDS had killed about 1, 2-million people, according to the Actuarial Society of SA. In that year, it was responsible for an estimated 70% of adult deaths – some 311 000 people.

And people claim to have AIDS fatigue and don't want to know about it? Does that mean that we like funerals to be the focal point of our social lives?

The second Nelson Mandela-HSRC household survey on AIDS was released late last year. It is the most definitive piece of research on HIV that we have, with blood samples drawn from over 8000 people as well as their views on HIV and their sexual habits. But somehow in the hype of World AIDS Day, it scraped by on a few small news stories. If you want to be informed about the pandemic, do yourself a favour and read it. Many, many story ideas are imbedded in those statistics. (Check out [www.hsrc.ac.za](http://www.hsrc.ac.za))

Last year, in this forum – and almost everywhere that I speak on AIDS – I was asked why black women are the face of AIDS in this country and why it is that “the media” (that is usually code for white journalists) never portrays white people with AIDS.

Well, statistically young black women, particularly those living in informal settlements, are the group most affected by HIV and AIDS by far. What should anger you and I is not that “the media” is trying to scapegoat black women but that, because of the inequality that continues to flourish in our country, black women are the most vulnerable to this sexually transmitted disease that can be prevented relatively easily.

In 2004, almost a quarter of young women aged 20 – 24 were HIV positive, while 9.5% of men that age had HIV. This gap only closes at 30-39, when men start to be more infected than women.

So what are the narratives that remain in HIV/AIDS? How about starting with the basics: a story of what life in an informal settlement is like for a young woman, and whether “Abstain, Be faithful, Condomise” resonates at all for her and her friends.

Many of us think that the struggle waged by the Treatment Action Campaign for access to free antiretroviral drugs is over. But my colleague Yolisa Njamela reminded me of how far we still have to go recently when she came back from Mthatha Hospital and revealed that the pharmacist is only dispensing 10 new ARV scripts a week so many people are dying while on the waiting list for ARVs. We tend to think the struggle is over because people have the right, in theory to ARVs. In practice, most don't have this access. At the same time, the Health Minister's continual questioning of whether ARVs works drives the desperate into the hands of those selling untested concoctions such as uBhejane.

Adam Levin's book, *AIDS Safari*, is a graphic first-hand account of what it is like to live with AIDS. Read it and be appalled by the suffering that is endured in virtual silence by the majority of those with AIDS, who are made to feel ashamed that they have a disease by the fake Christian morality that seems to prevail, in which most adults have sex yet “thou shalt not be caught” and shame on you if you are.

There are some fascinating theories about why people in southern Africa are so vulnerable to HIV infection – to do in part with circumcision not being part of certain cultures (circumcision substantially reduces men's vulnerability to infection) and to do with the habit of many men (and some women too) of having more than one “steady”

partner, which means infection is easier to transmit. (Not that we are more promiscuous. Brazilian men have more sex partners in a year, for example. But these tend to be one-night stands, rather than concurrent affairs). Surely this is interesting? Don't we always love other people's sex lives?

And then, the saddest of all, the AIDS orphans who are growing up without parents to guide them. In 2004, there were an estimated 626 000 AIDS orphans, some of which are growing up in houses run by children alone. Many teenage orphan girls are being sexually abused, and having babies themselves – when they still need mothers to take care of them.

AIDS fatigue? We are just not trying hard enough to tell these stories in interesting ways. We are also making a number of mistakes, including:

- We are failing to see AIDS in context.
- AIDS has been relegated to health instead of being incorporated into all beats.
- We lack understanding of scientific principles, allowing ideology to replace science.
- In our desire to appear balanced, we have elevated notions that have little scientific standing.

## **Chronic 'lifestyle' diseases**

We also have 'lifestyle' diseases inflicting the US and Europe in epidemic proportions. This usually refers to diseases such as diabetes, high blood pressure and heart problems – and is medical code for “it's all your fault that you're sick”.

Well, is it our fault? Yes, we are getting fatter and more sedentary, and this is causing an epidemic of heart disease, diabetes and hypertension. But the massive growth in chronic diseases in SA speaks of people who are living through a transition, people who:

- have moved from rural places where they had to walk long distances to urban areas with better transport systems and where it is simply not safe to walk around
- have changed their basic diet from home-grown vegetables to starch and sugary foods;
- buy fatty meat and soft drinks because they are cheap
- go to schools that have no sports fields, equipment or teachers.

There has also been the globalisation of fast food chains, and the definite strategy of marketers to move from the saturated markets of the US and Europe to the “developing world”, which is now being aggressively targeted by soft drink companies, fast food chains, tobacco companies etc. Smoking amongst women in the Western Cape is one of the highest rates among women in the world.

When I heard of how fat people in the US were getting, a perverse part of me was pleased that the nation that feeds off everyone else was now choking in their own over-indulgence. But it is not the rich who are getting fatter but the poor, who live in poor

neighbourhoods without play areas, who cannot afford gym memberships and who live on junk food because it is cheap.

In South Africa, it is possible to have a stunted child who grows up to be an overweight adult, or to have both in the same household. The child will not be getting enough nutrients from his or her diet to grow properly, with the adult's body will be used to not having enough food so will tend to store whatever food it gets as fat in preparation for the lean days ahead.

Ironically, older black women and older white men are the fattest adults in SA. Mama Lindiwe eats mainly pap and Oom Piet likes his beers. But they both share a love of fatty meat and neither likes to exercise. Is there a nation-building story in that?

## **Homicide**

Death doesn't always come with disease. We are pretty good at killing one another too. If any of you have had the misfortune of spending time in the casualty ward of a government hospital on a weekend, you would know that. Parents tend to want to lock up their daughters because of the very high rape rate. But we should also lock up our sons because a very high proportion of young men die violent deaths.

After AIDS, homicide and violence is our second biggest killer overall after HIV/AIDS. In 2004, about 12% (some 60 000) deaths were due to non-natural causes. The causes of these deaths were split almost equally between traffic accidents (40%) and homicides (40%), with suicides accounting for 11% (National Injury Mortality Surveillance System report, 2004).

Men accounted for a staggering 80% of unnatural deaths, with the leading cause of death in boys and men from the age of 15 to 44 being violence.

And criss-crossing the tragic pattern of homicide is our own special demon – alcohol. When did you ever see a narrative that did anything more than tut-tut faintly at the addiction that is tearing our social fabric to shreds? Alcohol is the standard accomplice in crimes of domestic violence, rape (particularly gang rape), traffic accidents involving both drunk drivers and drunk pedestrians and homicide.

What does it say about our nation, this violence and widespread substance abuse? What does it say about our government that can come down viciously on cigarettes and tobacco companies but seems to turn a blind eye to what alcohol is doing to us? (Has anyone every heard of a woman being gang-raped because she had been with men who had smoked one too many cigarettes?)

## **Psychological disorders**

Before moving off our litany of ills, I have to mention and underscore and highlight the most neglected area of all: our psychological illnesses.

Again, substance abuse is a major culprit here. There are virtually no rehabilitation centres for poor people with substance abuse problems. About 18 months ago, I wrote about a facility in the Western Cape that takes a few kids. I still get emails every week asking about the place. How is gangsterism in the Western Cape ever to be dealt with when there is absolutely no way for young people trapped by drugs to escape?

A study done in Khayelitsha a few years back found the rate of post-natal depression to be almost double that of developed countries. We have high rates of post-traumatic stress disorder linked to violent past and present. It is not normal for all of us to know someone who was murdered. We are no longer officially at war, but violent crime, particularly rape, leaves psychological scars that affect the well-being of families.

On the far extreme, are people with psychiatric illnesses. But government has a policy of “deinstitutionalisation” which means that those who are used to being cared for in institutions are sent to ill-equipped families, they relapse and go back to square one, but there is no space for them in the institutions any more...

## **What else?**

### **Health systems**

These are the some of the big news health stories in South Africa that show how our social fabric is being destroyed. But there are millions of other stories that can be written. A big one that is addressed fairly often and is probably the one we do reasonably well, is how patients experience the health system.

[Extract: NYT “The doctor will see you for exactly seven minutes”]

In some SA hospitals, you’ll be lucky to see a doctor and 7 minutes is a luxury. In big public hospitals, doctors seldom see the same patients. There is no follow-through. Doctors do not know whether their interventions have worked – and there is unlikely to be much censure if they mess up.

Is it surprising then that people are flocking to complementary and traditional healers, who spend time listening to them?

### **Science**

Then there are the science stories. The MRC and other academic and government institutions, aware that the country needs to encourage young people to become scientists, are putting some effort into getting scientific information to the public. But much of it is hard to digest.

Narrative writing can help a great deal. Atul Gawande, a surgeon who is also a brilliant writer, has written a book “Complications: A surgeon’s notes on an imperfect science” which has some brilliant accounts of surgical procedures and diseases, bringing them to life through patients.

Chronic pain is becoming a huge problem and a major cause of people missing work. But what is pain? How do people experience pain?

[Gawande extract pg 115]

## ***Helpful techniques***

So many story ideas but how do we put them together into compelling narrative?

Jon Franklin, who wrote Mrs Kelly, explains that he used “the classic short story structure” to construct his piece, with a “main character, character complication, a development, a point of insight and a resolution”.

US journalist Walt Harrington talks not about narrative but “intimate journalism”. This he describes as “news you can feel”, which aims to “describe and evoke how people live and what they value”.

Harrington offers a few basic techniques to achieve journalistic intimacy, and I have adapted and paraphrased some of these:

- Thinking, reporting and writing in scenes. (This means gathering together a series of actions/ conversations and putting them together.)
- Capturing a narrator’s voice and/ or writing the story from the point of view of one or several subjects (deciding on whose view prevails. In “Mrs Kelly’s Monster”, Franklin aimed to make Mrs Kelly the main character but when she died, he decided to make the surgeon the main character.)
- Gathering telling details from our subjects’ lives that evoke the “tone” of that life.
- Engage all five senses: sight, sound, taste, smell, touch. Readers have been found to engage far more with a story if two or more of their senses are engaged.
- Gathering real-life dialogue. (We usually report on what people have told us, which means we are relaying this to our audience. But if we report on what people in our stories say to one another, not to us, both we and our readers become the audience.)
- Gathering “interior” monologue (not just facts but the meaning these facts have for our subjects. Why does our subject put that on her wall/ How did it make him feel when told he was HIV positive?).
- 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. (This means spending enough time with them and having conversations with them rather than interviews.)
- 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. (A camera can help us to remember.)
- 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.

(Adapted from “Intimate journalism: The art and craft of reporting everyday life”, Walt Harrington).

Some of my personal no-nos include:

- Reporters inserting themselves with a big fat “I” into stories if there isn’t a very good reason for them to be there. I feel it deflects attention from the subject, interferes with what is happening and sometimes feels like being in Oprah’s confessional in which the reporter’s ego becomes the subject.
- Sticking mechanically to prepared questions, or trying to fit your story into a hypothesis you’ve formulated in the office. My desperation for something – anything – that can work to prevent the spread of HIV means that even when I cover uBhejane, garlic-and-olive-oil diets, I have this little hope that it might work. Keep an open mind.
- Conversely, never take the word of people profiting from their version of reality (either financially, as the maker of uBhejane is, or by becoming important, as has the garlic nurse through her association with the Health Minister). Be sceptical and find other versions.
- Don’t make it up. It is tempting to make your subject more articulate or to polish their “rough edges”. But then you should write fiction