

Analysis of deaths on Matthias Rath illegal clinical trial

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Summary

- Analysis of five deaths of patients on Rath's trial
 - For three of these patients Rath is at a minimum responsible for contributing to their deaths.
 - For the other two, Rath is at a minimum responsible for misleading them and creating false hope.
- Several other deaths on Rath's trial have been reported, but we only discuss here ones which we have investigated.
- Minister of Health has responsibility for failing to stop Rath.
- Rath's pseudo-science in conjunction with other pseudo-scientific practices throughout South Africa is causing confusion and costing many lives. This pseudo-science flourishes because it is perceived to be endorsed by the Minister of Health and President Mbeki.

Matthias Rath is a pharmaceutical proprietor who claims that micronutrients alone treat AIDS. He claims that antiretrovirals, the treatments recognised by every competent medical authority for treating HIV/AIDS, are toxic and make AIDS worse. He makes similar claims for heart-disease, cancer, diabetes and other diseases.

Rath has in conjunction with his agents --which include some South African National Civics Organisation (SANCO) branches, Anthony Brink, David Rasnick, Sam Mhlongo and others-- conducted an unauthorised and illegal clinical trial in Khayelitsha and other areas in the Western Cape. This trial involves making false claims to prospective patients that vitamins reverse the course of AIDS, taking blood samples from patients, taking photographs of patients semi-naked for the purpose of before and after photographs and distributing unregistered drugs to patients. Rath's drugs, according to their labels, consist of vitamins, amino acids, a schedule two substance called N-acetylcysteine and other micronutrients. Based on affidavits we have received, these drugs are prescribed in unusually high dosages. This is in line with Rath's stated theories and past practices.

TAC has confirmed and analysed the deaths of five people who have died on Matthias Rath's illegal clinical trial. In two of these cases, Rath is at least responsible for having created false hope. In the other three, Rath is partly responsible for their deaths. In at least two further cases, patients held up by Rath as models of success on his programme were, and are, actually taking antiretrovirals. These two patients are alive.

TAC supports government's rollout of antiretroviral treatment. We also support the policy of making multivitamins available to people with HIV in the public health sector. But we take a dim view of people who claim or imply that the risks antiretrovirals outweigh their benefits or who make unproven claims about their own products.

Case one - the death of Marietta Ndziba

Ndziba was used --and continues to be used-- by Rath for marketing his products. In a pamphlet distributed by Rath and his agents in September, she was quoted as saying that her CD4 count rose from 365 to 841 due to Rath's vitamins. She implied that these vitamins treated boils on her arm, her grey skin, diarrhoea and vomiting. She said *"I just thank God that he brings vitamins here to South Africa to help our lives."* As far as we can ascertain Ndziba never took antiretrovirals. She died about two weeks ago. Her family continues to be in denial about the cause of her death, with one family member reportedly claiming that she died of a stress headache. Rath's vitamins clearly did not help Ndziba. She should have been treated by qualified doctors in the public health system, not Rath or his agents.

Astoundingly, a video recording of Ndziba claiming the benefits of Rath's vitamins continues to be available on the front page of Rath's South African website to this day.

Case two - the death of Ntombekhaya (we withhold her surname to protect her family's privacy)

Ntombekhaya commenced treated for TB in 2004 at a public health clinic. She was HIV-positive and was going to start antiretroviral treatment once her TB treatment was completed. Her CD4 count was 45 in October 2004 and she had lost weight. In early March 2005, she made contact with Rath's agents. From that point she stopped taking medicines from the Site B public health clinic in Khayelitsha. She was quite sick when she started taking Rath's drugs, and she started becoming much sicker. Her health deteriorated under the care of the Rath Foundation. It has been alleged that they put her on a drip at one stage. Her family member caring for her was advised by Rath's agents not to call an ambulance if she got sicker, but to call them instead. She died on 27 March. Rath and his agents are partly responsible for her death by taking her off the medicines she was taking at the Site B clinic at a time that she was critically ill and delaying her initiation of antiretroviral treatment. We have confirmed the details of this case.

Case three - the death of Patient X

Patient X presented at Nolungile HIV clinic on 30 September 2005. He was in such a deteriorated state due to advanced AIDS that his treating doctor investigated his clinical history. Here it is:

He was admitted to Jooste Hospital on 12 September 2005. His baseline CD4 count was 22 and he had a haemoglobin count of 2. He required three blood transfusions. He was diagnosed with HIV encephalopathy and disseminated tuberculosis. It turned out that Patient X had been treated by a Rath clinic for two months prior to presenting at hospital. It is during this critical period that he missed an opportunity to be treated in the public health sector. He died on 8 October 2005. He never had an opportunity to commence antiretroviral treatment because he had not recovered from his several opportunistic infections.

Rath is at least partly responsible for Patient X's death by having caused his delay in seeking assistance from the public health system.

Case four - the death of Noluthando (surname withheld at this stage to protect family's privacy, but family is prepared to go public)

Noluthando was diagnosed with HIV in 2002. She lived openly with her status. At some point in April or May 2005, Noluthando made contact with Rath's agents. At this time she had stomach pains, but no other symptoms of illness. For three days she took 20 of Rath's VitaCell pills a day, far in excess of recommended daily allowances for many of the substances that the VitaCell label claims are in the pills. In these three days her condition deteriorated dramatically.

She could not walk without assistance and could not work. She therefore stopped taking the tablets. She was admitted to Karl Bremmer Hospital and died on 2 June 2005.

In this case, Rath is at a minimum responsible for creating false hope by claiming that his medicines would improve Noluthando's health. We are not sure if his tablets were responsible for Noluthando's deterioration in health, though given the large untested doses, this cannot be ruled out. It is unlikely that Rath delayed Noluthando from initiating antiretroviral treatment. Her involvement with Rath and agents appeared to be short. She was on a waiting list for antiretroviral treatment at the time she died. She is one of the many people who slipped through the cracks of a public health system under strain. It is such people who are most at risk of being taken advantage of by charlatans.

Case five - the death of Noxolo Ngalo

Noxolo Ngalo was diagnosed with HIV in January 2005. In April, she made contact with Rath's agents. She started taking 30 Rath tablets per day. At some point her dosage was reduced. Rath's spokesperson claimed on ETV that she only took Rath's medicines for 9 days. But this is contradicted by her mother who tells a coherent story of her being involved with a Rath clinic in Du Noon until at least August and possibly beyond, and that she continued to take Rath medications. Rath's agents would pick her up and take her to the clinic. They were supposed to pick her up on 5 October but did not arrive. They also informed her that she should not take antiretrovirals. Her condition deteriorated remarkably in the time that she was on the Rath trial. For example she began having epileptic fits. She went to hospital and was diagnosed with TB. She began TB treatment but her CD4 count was extremely low (approximately 15), her condition deteriorated, she suffered memory loss and stopped talking. She died of a combination of liver failure and AIDS-related conditions on 5 October 2005.

We cannot know if Rath's high-dosage drugs contributed to her illness. We also cannot ascertain if the fact that she never initiated antiretroviral treatment --even though she was earmarked for such treatment-- was partly a result of the false claims made to her by Rath's agents or the slowness of the public health system. But at a minimum Rath's claims that his vitamins would improve her health were misleading and created false hope.

Further reports

We have been alerted to several other deaths of patients on Rath's trial but have not been able to investigate these. We also have affidavits from two doctors working in the public health system describing confused patients who presented to them with Rath tablets.

But the deaths caused directly by Rath's trial are few compared to the numerous deaths caused by the pseudo-scientific confusion about HIV that is prevalent throughout South Africa. Doctors have frequently reported that many patients are too scared to initiate antiretroviral treatment or that they present too late to health facilities because they are so confused by mixed messages on the treatment of AIDS. Rath is just one contributor (a particularly serious one) to this confusion. Only with clear messages from our political leaders, including the Minister of Health and President Mbeki, can this confusion be alleviated.

Rath's dependence on anecdotal evidence

It might be argued that the above cases are anecdotal; they do not prove Rath's claims are false. Surely we need to examine statistical evidence to determine this? After all, no treatment can be 100% successful. It could further be argued that one can present plenty of cases of people who died on antiretroviral treatment, including directly as a result

of drug side-effects. But this misses the point. We know that antiretrovirals effectively treat HIV and reverse the course of AIDS by the results of numerous clinical trials and cohort studies published in prestigious, credible, peer-reviewed scientific journals. The results of these studies show that some people do not benefit from antiretrovirals, but more than 80% of people with advanced HIV disease do benefit from antiretrovirals.

Not a single peer-reviewed study confirms Rath's claims. There are no relevant statistics from Rath's trials. There cannot be, because we have determined in our investigations of Rath that there are no proper protocols in place or consistent drug prescriptions: sometimes patients are told to take 30 tablets a day, sometimes 20, sometimes just a few. They are also given different Rath products. Instead Rath, like other charlatans, depends on anecdotal evidence to market his theories. In doing so, he makes a point of counting his successful cases and ignoring his failures. We have presented the five cases above to counter the unproven propaganda claims based on anecdotes made by Rath. The available anecdotal evidence reinforces the unlikeliness of Rath's claim that his micronutrients reverse the course of AIDS.

False choices

In a number of radio interviews, TAC members have been asked the question: "But surely people are entitled to a choice?" Indeed, people are entitled to make choices about their health. We do not dispute that Marietta Ndziba had the right to choose not to take antiretroviral treatment. But neither Matthias Rath nor any pharmaceutical company has the right to make false claims that contribute to people making poor choices.

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-->The Minister of Health has also misused the concept of choice. In a written answer to a question in Parliament she has stated "*I have never said that traditional medicines and vitamins should be offered as alternatives* [she has unequivocally implied it on numerous occasions - editor], *which means instead of ART. What I have emphasized is that our people must be given a choice.* "

But the Minister's job is to present advice to the public based on the best available scientific evidence. It is then individuals who can choose whether to follow or ignore this advice. The minister should not present unproven options as valid choices.

Minister of Health's responsibility

There have been several complaints about Rath's activities lodged with the Department of Health including by TAC, MSF, health-care workers in the Western Cape and members of the public. We have compiled substantial evidence of a failure to act by the relevant authorities. We are convinced that this failure to act is a consequence of the Minister of Health's lack of political will. The Minister of Health has met with Rath alone and she has allowed his agents, David Rasnick and Sam Mhlongo, to present their theories to the National Health Council. She has made statements whose only reasonable interpretation is support for Rath. She has also consorted with other charlatans, such as Tine van der Maas, including voluntarily appearing in a propaganda video produced by van der Maas (partly sponsored by Rath) and showing this video at various forums.

The South African National Civics Organisation (SANCO) played an important role in the anti-Apartheid struggle. But the role of some of their branches in supporting Rath's activities has been unacceptable. Some SANCO branches openly support Rath. They are deeply involved in his clinical trial. They promote Rath in Khayelitsha, Hout Bay and other places. They recruit patients for the trial and use SANCO's name on the inadequate patient consent forms for the trial. These SANCO branches have a reputation for using intimidatory tactics against people they perceive to oppose them. Consequently, people with important knowledge of deaths on Rath's trials are scared to come forward. We have received several reports of SANCO members being paid by Rath to carry out his agenda.

If action is not taken to stop Rath in the next few days, TAC will be left with no choice but to proceed with litigation to seek interdicts against Rath's activities and a declarative order against the Minister of Health. Reluctantly, we might have to take the Minister to court yet again, but there is no choice: too many lives are at risk.

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