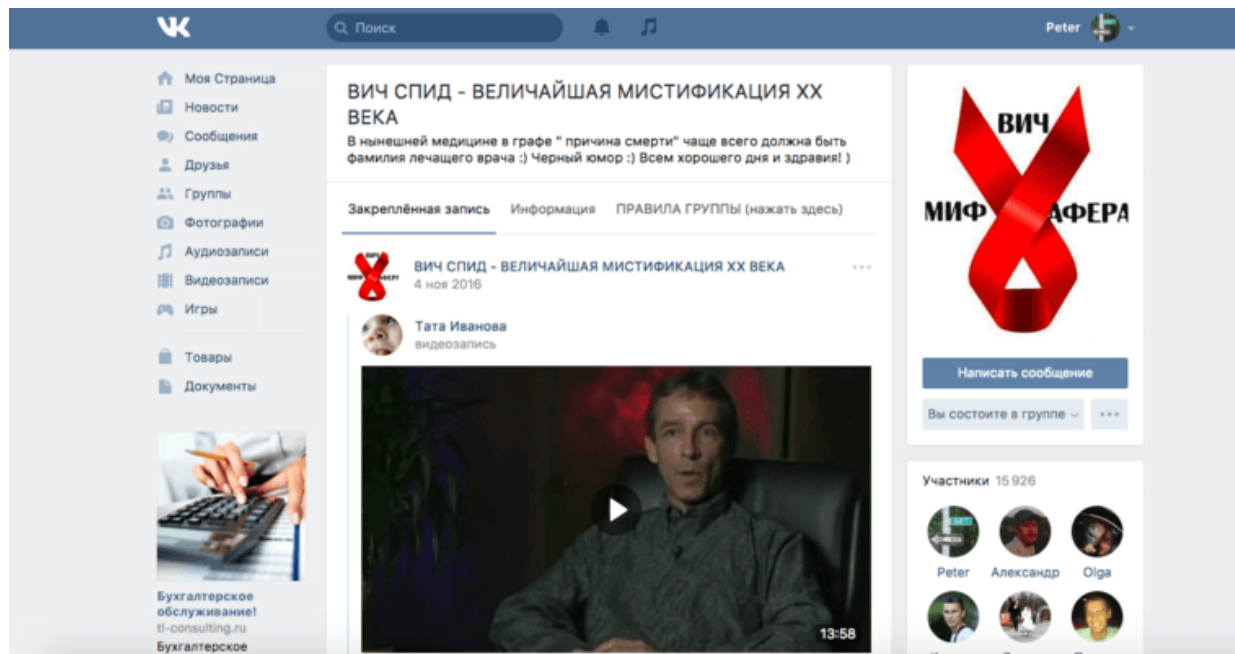


How AIDS denialism spreads in Russia through online social networks

April 3 2017, by Peter Meylakhs Et Al



The Facebook page of a known Russian AIDS-denialist community. VK, Author provided

The appointment of former president Thabo Mbeki as chancellor of [one of the highest institutions in South Africa](#) on March 1 has drawn much international attention. Mbeki [has been sharply criticised](#) for being a champion of [AIDS denialism](#) and held responsible for numerous deaths through his [policies regarding antiretroviral drugs](#).

AIDS denialists are people who believe the HIV virus does not exist and that AIDS is caused by a plethora of factors, such as drugs, malnutrition, stress, or even anal sex by itself.

While their arguments have been long discarded by the international scientific community, AIDS denialists reject scientific facts and claim that all the evidence of HIV existence has been concocted by corrupt scientists, who are on the payroll of Big Pharma, the "invisible world government" and so forth.

The phenomenon is not limited to South Africa. In Russia, [the media often reports on cases](#) of AIDS-denialist parents, who have refused to give their HIV-infected children [antiretroviral treatment](#), causing significant health damage or even death.

Nor is it limited to people without HIV. Indeed, the claim that AIDS is a hoax may be an irresistible one for HIV-positive individuals, especially those who are seeking to come to terms with a recent diagnosis of the disease.

AIDS denialists in the Russian internet

The rise of the internet and social media have given a new life to AIDS denialism: people searching for information on the virus find that AIDS-denialist websites or forums are just a click away. Often these sites assert that HIV is a myth, and that all you have to do about the disease is forget about it.

To understand how some HIV-positive individuals become AIDS denialists and what can be done about it, [we undertook a mixed-method study](#) of the largest AIDS-denialist community present on Russia's largest social network, [VKontakte](#). During the project's execution in 2016, [the group numbered](#) around 15,000 members and had existed for

almost eight years.

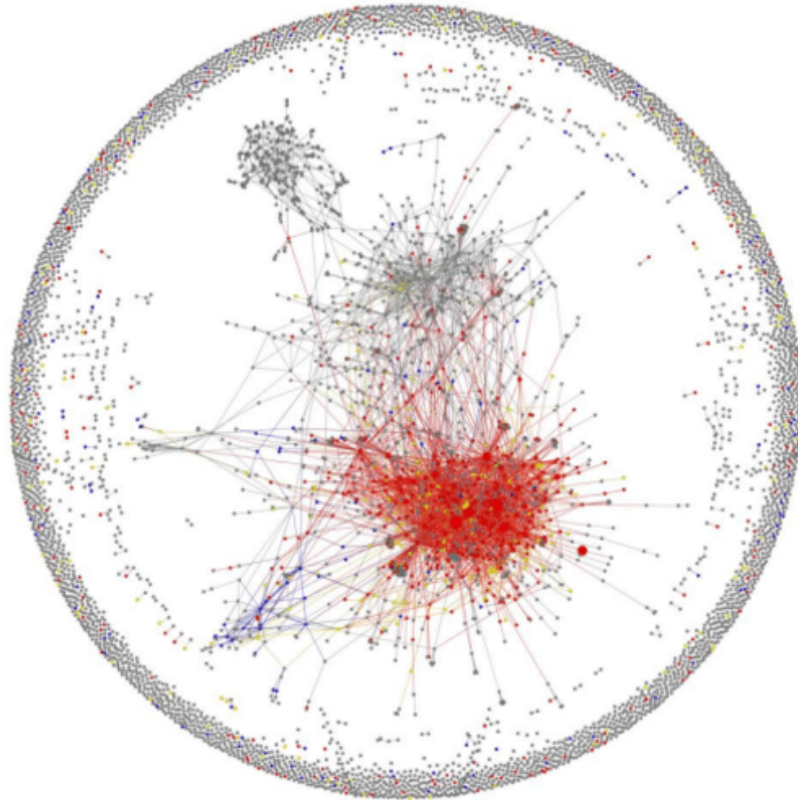


Fig. 1. Friendship network of group participants (red—AIDS-denialists; yellow—doubting members; blue—'orthodox' members; grey—unknown).

Credit: HSE/Authors, Author provided

We conducted ethnographic observation of the group over nine months and collected 25 semi-structured interviews with HIV-positive group members. Some were AIDS deniers, while others were former deniers who'd pulled away from the group's rhetoric and claims.

We [analysed](#) the AIDS-denialist group's network structure and [determined its "core", "periphery" and "susceptibles"](#) (those who are at a greater risk of becoming hard AIDS deniers).

The core consists of participants with a lot of friendship ties and communications (posts and comments) within the group. Periphery were those who had few friendship ties and were not particularly involved in communication activity within the group.

To our surprise, we found that the two most-known and hotly debated AIDS denial rhetorical strategies – that HIV science is fake and that it is a product of a global conspiracy – played almost no role in converting individuals to AIDS denialism. These arguments were used as rationalisation for their position, adopted for other reasons.

Why deny?

Three important factors were determined: inadequate counselling, denial of the diagnosis because informants "felt good" and unwillingness to follow antiretroviral treatment.

In contrast to their [portrayal as being completely irrational](#), some people who became AIDS denialists asked perfectly rational questions. For example, an HIV-positive woman, who had had unprotected sexual intercourse with her husband for eight years, asked how her husband remained HIV-negative. Others wondered how the immune system of an HIV-positive person improved without treatment.

Unfortunately, such questions do not get informed answers. Most Russians have a stereotypical picture of HIV and AIDS gathered from leaflets and posters in health clinics. Many still believe misinformation from early in the AIDS era, when it was thought that HIV-positive persons were highly infectious without sexual protection and that their

immune systems linearly deteriorate.

This may be a useful public health message, but the real picture is much more complex. HIV science has the correct overall picture – HIV does cause AIDS and untreated HIV infection leads to AIDS – but, as in any science, there are a lot of nuances and unknowns.

For example, we found that when people ask their doctors such questions, they often face an arrogant and paternalistic attitude. Instead of explaining to their patients the complexities of the disease's progression and admitting that not all questions can be answered by current science, Russian doctors often say something like "I'm your doctor, and you're my patient. Your role is to do as I say, not to ask questions."

Unsatisfied, HIV patients then look for information on the internet, where they can fall prey to AIDS denialists who give them clear but false answers to their questions, such as "Of course you haven't infected your husband, because the whole HIV story is fake."

What can be done?

Sadly, our research indicates that little can be done to help hardcore AIDS denialists; attempts to better inform them only strengthened their erroneous beliefs.

All study participants who were former AIDS denialists said that it was only when their physical condition had deteriorated dramatically – some of them had balanced between life and death – that they realised that AIDS was real. Only then did they seek treatment. Sometimes the change of heart was too late; several group members died of AIDS despite eventually seeking treatment.

The best way to prevent individuals from being tempted by AIDS denialism is to provide good quality, patient-centred counselling and properly manage treatment side effects.

For those who are still in throes of denialism, our study came up with the following recommendation: "Believe whatever you want but check your immune status. Just in case." This can help bring a patient closer to getting care, hopefully before it's too late.

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