

The original story in Chinese was published on The Paper (Peng Pai). Please see [https://www.thepaper.cn/newsDetail\\_forward\\_2268059](https://www.thepaper.cn/newsDetail_forward_2268059). Below is the English version. Graphs here are all in Chinese but I make explanations in the note.

## **Living In The Shadow Of AIDS Phobia**

Waking up again in panic at 3 am, Elizabeth rushes to the bathroom, touches her neck, checks her tongue in the mirror, and every other early symptoms of AIDS. She feels relieved that nothing is wrong but then fails to fall asleep again.

Elizabeth has been suffering from the mental health problem called AIDS phobia since her first sex experience. She cannot overcome an inner feeling of dread, though knowing clearly that her boyfriend couldn't carry HIV. "It's a mental issue," says Elizabeth. "My brain feels sick."

"I couldn't build up the courage to walk into a hospital... I've been to three general hospitals, to one infectious disease hospital, and CDC for many times. It makes me exhausted to take blood tests every month – but I can't stop otherwise I will be caught by the scary monster again," she writes on Weibo.

### **Half a million patients, at least**

Elizabeth is not alone. There had been more than 10 million posts and 75,000 followers by the end of 2017 on Baidu Tieba "Fear of AIDS", one of the most popular AIDS-related forums.

"AIDS phobia is defined as the irrational fear of getting infected with HIV despite evidence to the contrary." Dr. Zhang from Chengdu Fear of AIDS Intervention Center says, "Everyone's afraid of AIDS. AIDS phobia only refers to the cases where patients' daily lives are seriously affected."

At least half a million Chinese are suffering heavily from AIDS phobia, Dr. Zhang estimates. "Flying Bird", a volunteer trying to save people from the phobia, believes that there might be tens of millions of AIDS phobia patients here -- the former owner of Tieba "Fear of AIDS" once told him that their site got a million hits every day.

Top tier cities, such as Beijing, Shanghai and Guangzhou, hold the largest number of AIDS phobia patients, while people living in Sichuan, Henan, Xinjiang and

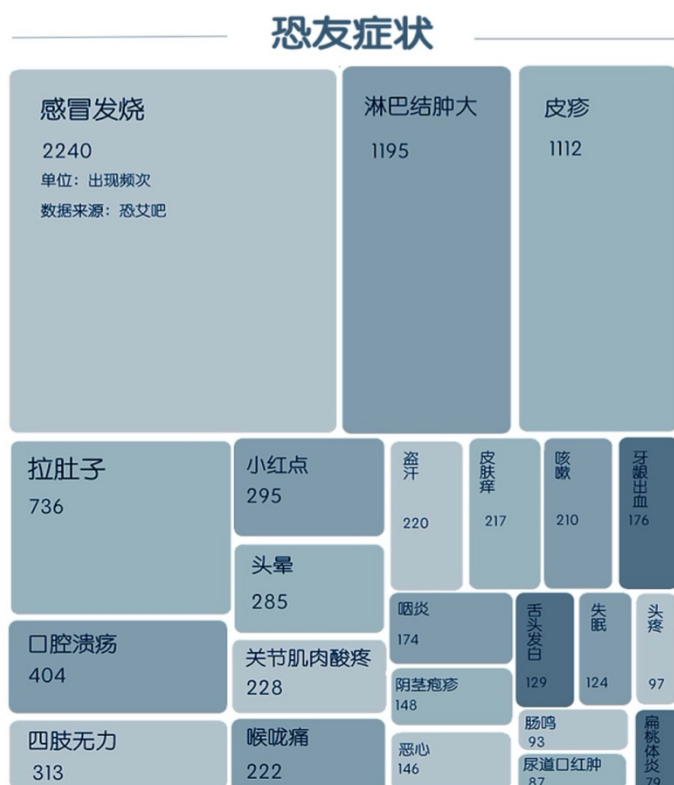
Yunnan are more likely to be caught in the phobia due to a wider AIDS awareness there, according to statistics data gathered by Chengdu Fear of AIDS Intervention Center, the biggest institution providing aid to those patients in China.

Data also shows that the male-to-female ratio in the group is around 4:1, and youngsters in their 20s make up the majority of AIDS phobia patients. Flying Bird says people of this age group are most easily affected by mental health under the pressure of work and life. Fear of HIV infection is kind of a carrier of their mental anxiety.

Such a large group of AIDS phobia patients, may have something to do with the early threatening AIDS policies of Chinese government, which have stigmatized AIDS and penetrated subconscious panic into people's mindset, according to Dr. Zhang and Flying Bird.

To most people, AIDS is seen as a 100 percent fatal infectious disease. The early symptoms of AIDS, such as fever, headache, fatigue, vomiting and diarrhea, are similar to those of a common cold. If one searches for those symptoms online instead of seeing a doctor, getting cold can be easily mistaken for HIV infection.

Most patients Dr. Zhang knows are college students and highly educated white-collar workers. "They know how to get access to information on the Internet, which turns out to make things go off track instead."



*Note: By analyzing 12,379 posts (more than 1.4 million texts in total) that were crawled on Tieba "Fear of Aids", we found those symptoms which people there consider as the early symptoms of HIV infection. The biggest ones: get a cold, have a fever, swollen lymph nodes, diarrhea, etc.*

"Can the blood from a mosquito get me infected with HIV? "

"I swatted a mosquito but there is a small cut on my hand. Can the blood from the mosquito get me infected with HIV? I wish I hadn't killed that mosquito..."

"I had sex with a woman who just ended her period. I saw blood on her sanitary pad. Will I have AIDS in this case even if I used a condom? "

"Anyone here can help me out? I never used condoms before when having sex with my girlfriend. I just somehow worry that I might be infected though I haven't had any symptoms yet..."

This kind of posts take up a large proportion in Tieba "Fear of AIDS". Among the 12,379 posts we have analyzed, consulting ones are up to 7,089 (57.2%). The rest of the posts are mostly sharing personal stories and regret.



*Note: The graph gives a glimpse of "high-risk behaviors" people described in their posts in Tieba "Fear of AIDS". It is their misunderstanding of high-risk behaviors that drives them into AIDS Phobia. The most frequently used words are: sex, condom, blood, blow job, cut, saliva, hooker, tongue, etc.*

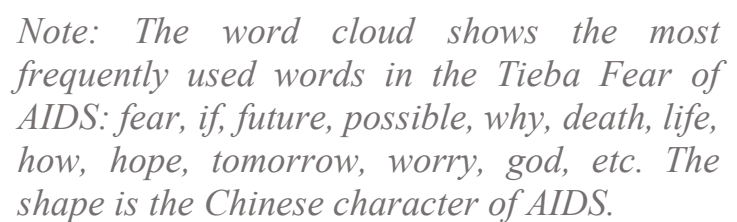
Most of the high-risk sex behaviors people worry about are not risky at all. HIV can only be transmitted through direct exchange of body fluids. It cannot be transmitted through air, droplets, food-borne, or mosquito bites. It can by no means be transmitted by kissing and the presence of mouth sores, bleeding lips, gum disease, etc, do not change this.

High-risk behaviors have two prerequisites. First, there must be direct contact with HIV infected people. Second, there must be direct exchange of body fluids

Many suffering from AIDS phobia worry about eyebrow shaping, manicuring, sharing makeup tools with others, or touching strangers with a cut on hand. Their misunderstanding of high-risk behaviors shows a lack of medical knowledge among the general public, says Dr. Zhang.

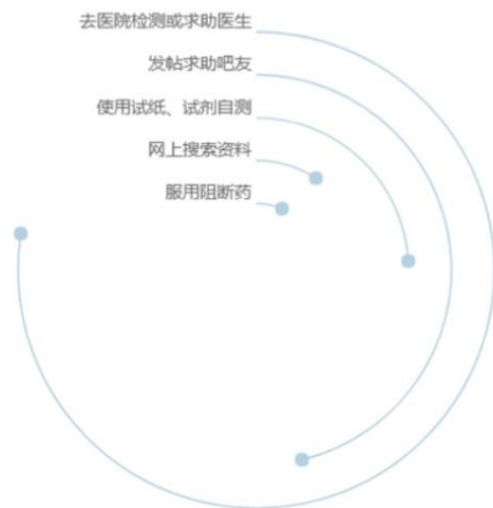
Elizabeth divides the phobia patients into two groups: some do have high-risk behaviors, while others are just over-suspicious, like herself. Elizabeth could not stop her fear though knowing clearly that she is by no means infected. "It's more of a mental illness."

Liu Tao has suffered from AIDS phobia for ten years. He caught a cold seven years ago and searched online for any prescription, only to be scared by the similar early AIDS infection symptoms. In the darkest of days, he even made a pact with other patients to "commit suicide if infected". The negative test result only saved him for a while – he turned to believe that the virus in his body escaped detection in the blood test.



## Recovering from phobia is a war

Many will choose to take tests in hospital or CDC when worrying about the possible infection. However, it takes from four weeks to six months to get the results, which means mental suffering for at least a month is inevitable.



*Note: By analyzing the posts, we summarize five ways for AIDS phobia patients to get rid of their fear, among which "seeing a doctor" is the main way to seek help while searching online for information is the fourth one.*

The test result can help some to get out of fear. But for people like Elizabeth and Liu Tao, test results and doctor diagnoses are far from enough. They need more of psychotherapy to escape the trap of phobia.

A relapse makes Liu Tao's situation even worse. He locks himself in a small room, refuses to get out, escapes from normal social life, and keeps crying day and night. He ends up being sent to mental hospital by his family after a failed suicidal attempt.

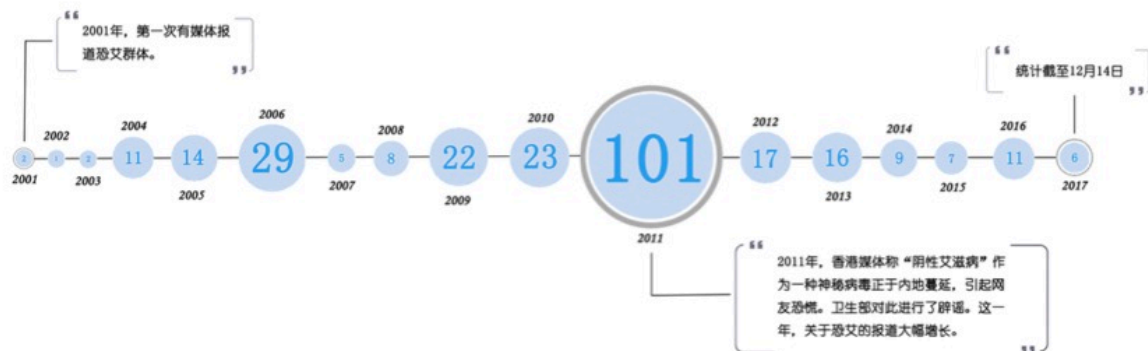
Just like the cases of other mental illnesses, relapse is fairly common among AIDS phobia patients. Elizabeth has experienced several relapses and breakdowns due to a broken relationship, insecurity, or just a bad mood out of nowhere – everything could be the final straw.

Psychological intervention is necessary for patients like Liu Tao and Elizabeth. But they only trust physicians with expertise in AIDS treatment, leading to a dilemma – "the physicians who know AIDS are not familiar with psychotherapy, whereas the psychologists may not know AIDS treatment. A combination of both is needed," says Flying Bird.

"People used to seek help from VTC (Voluntary HIV/AIDS testing and counseling), but it does not provide any psychological support. That's why

Chengdu Fear of AIDS Intervention Center is established in 2009," says Dr. Zhang.

The Center is currently the only one specialized AIDS phobia intervention institution in China. However, "Chinese government has not issued relevant policies yet to support the intervention of AIDS phobia, though they finally approved the Center as the country's first research project in this area in late 2017", according to Dr. Zhang.



*Note: With "AIDS phobia" as the keyword, we crawled and analyzed a total of 325 news articles in Chinese through Baidu, 284 of whom are left after deleting repeated ones and blog articles.*

Chinese media coverage of AIDS phobia has remained at a low level since the first time it was reported in 2001. Hong Kong media once reported "negative AIDS" as a mysterious virus spreading across the mainland in 2011, causing a small panic on the Internet. The Ministry of Health later dispelled the rumor, pointing out that "negative AIDS" is a symptom of AIDS phobia. Public attention on AIDS phobia reached the peak that year, which unfortunately didn't last long. There are only 10 news reports in total on AIDS phobia in Chinese mainland media this year.

Zheng Lin, a correspondent from Beijing Youth Daily, who once reported on AIDS-phobic people on World AIDS Day 2016, admits that the media focus on the AIDS groups only around the AIDS day. Moreover, the reporters' attention, if any, would be more likely on the HIV infected people instead of phobia patients.

AIDS phobia is such a complex problem that needs patients, families, doctors, phycologists, institutions and the government to work on together. "lack of publicity, counseling, professional doctors and domestic sex education," all are the barriers we need to overcome, says Flying Bird.



Recovering from AIDS phobia can be a war for at least half a million patients. Dr. Zhang gives some advice – "the first step and the key is to keep yourselves away from online information. The patients then need a reliable doctor or psychologist who can provide them with correct information. Last but not least, the patient needs to realize that their phobia is more of a mental illness than a physical one."

Elizabeth finally escapes the fear trap. It is the company and love of her friends that helps her through dark periods. Every moment with friends was a "last supper" for Elizabeth, who at the time believed she had AIDS. The friendship gives her the courage to face the "incurable illness" and leads her out of the puzzle step by step.

Elizabeth is one of the lucky few. There are still tens of thousands of unlucky ones who are helpless trapped in the deep fear. Feeling anxious, guilty, insecure and depressed, they have an atypical mental illness but do not know how to treat it. The shadows keep following them and the night won't set them free. They are desperately yearning for the help.