

The burden of truth

Despite years of official harassment, activist Gao Yaojie is still battling for the rights of mainland Aids sufferers. Here is an extract of her autobiography, translated by Violet Law.



Cover story

In the mid-1990s, gynaecologist Gao Yaojie, now 81, was called into a hospital in Henan province when baffled physicians grew concerned about a patient's condition. The woman died a few days later, by which time Gao had traced her ailment back to a blood transfusion.

From that incident, Gao has gone on to become arguably the mainland's most well-known Aids activist. New York Senator Hillary Clinton interceded on her behalf when, in 2007, she was prevented by Henan officials from visiting the United States to collect an award from the Vital Voices Global Partnership; one of a several international accolades bestowed on the woman *Time* magazine has dubbed Grandmother Courage. Her recently published autobiography, *The Soul of Gao Yaojie*, is being translated into English. Here is an exclusive extract:

"IN THE 1980s, when I heard of Aids, I mistook it for the exclusive domain of drug addicts and the promiscuous, because that was what the media and the government reported. But facts on the ground would soon change my view of how Aids was being transmitted in China.

In the mid-1990s, I began to run into patients who had contracted Aids through blood transfusions. They were all innocent women. I was stunned. When I came into contact with even more HIV carriers and Aids patients, I realised this was in fact a nationwide epidemic.

As a doctor I couldn't turn a blind eye; I had a responsibility to do all I could to prevent this

epidemic from spreading. However, at the time, I was unaware of the unfathomable forces underlying the widespread transmission of HIV. Had I known, I might not have been able to muster the courage. It's been 12 years since I threw myself into this work and since then I've been on a treacherous path to raise the awareness of people both in and outside the country.

An army hospital in Zhengzhou [the provincial capital of Henan] had admitted a female patient with the last name Ba, who had lumps in her abdomen and a stubborn high fever. She had remained undiagnosed for 16 days. On April 7, 1996, the hospital asked me to come and see the patient. I gave her a full examination. Looking at the purple spots on her skin, I suspected Kaposi's sarcoma (a kind of tumour caused by the herpes virus and one of the defining illnesses of Aids).

When I asked her primary physician to test her for HIV antibodies, the doctor refused, saying: 'You didn't do a thorough job examining her and randomly thought of Aids. Why on Earth would there be an Aids case around here?'

I retorted: 'The patient is so ill and yet she still doesn't have a diagnosis. We haven't been able to help her so we should keep at it. If you don't draw her blood tomorrow for an HIV test, don't ever call me again.'

On April 10, Ba's test results came back positive. The entire hospital boiled over in anxiety. Everybody became nervous; some nurses were afraid to touch medical documents brought over by patients' families. When I learned of the results I was puzzled; Ba's husband was HIV negative.

Twelve days later Ba died. She was 42. Ba's

husband brought along a cot and her favourite food and slept in front of the tombstone for nearly two weeks, in the rain.

The husband explained what had happened: 'After an operation to remove ovarian cysts she suffered a lot. To help her recover, I asked the doctor to give her a blood transfusion. Who would have thought that would give her deadly Aids?'

Her death made me realise how Aids had been spreading through the blood bank and foretold a larger disaster. The death ignited my courage and spurred me on a journey to prevent Aids. This was my duty as a physician and my duty for my country. After Ba's death, I inquired about Aids cases in hard-hit cities and villages in the province. I was able to zero in on the source of the virus: plasma.

Since the 1980s, it had been a common practice in many villages to make money out of plasma. Banners exhorting villagers to give blood – for rewards and glory – were everywhere you went. Village officials went on television to lecture the public on the benefits of giving blood for pay.

Blood-transfusion stations had sprouted up. Workers there would pool plasma of the same blood type into one centrifuge. After the platelets were extracted, the mixed blood, with a saline solution added, was put back into the blood sellers' bodies. So if one of the sellers happened to have HIV, none of them could escape infection. The number of Aids cases snowballed – and they were not confined to provinces bordering Henan, such as Anhui, Hebei, Shaanxi, Shanxi and Shandong.

Here is just one example of what I observed during a field survey of the epidemic conducted between 1999 and 2000:



There were three blood-collection stations in Xincai county, in Henan's Zhuma district, operated by the People's Liberation Army hospital, the Chinese Red Cross and Xincai county's People's Hospital. The population of the county's seven villages totalled 3,000. At the peak of the platelet trade, an estimated 1,500 got by by selling blood. The villagers said at least 800 of them had Aids.

[In another case,] in 1996, the day after the May Day national holiday, a student of mine told me how relatives of her husband – a family of four – had been dying of Aids. After several phone calls, I finally reached the only surviving family member, the wife, to learn the whole story.

How did the Chen family get infected? The husband was from a fishing family and knew next to nothing about medicine or sterilisation but he knew how to make a profit. He set up a clinic to treat sexually transmitted diseases (STDs) and some of his patients must have been HIV carriers. Chen had to entertain local officials who protected his business interests by treating them to nights out with sex workers; so he may have contracted Aids through a prostitute.

His wife was most likely infected by Chen during intercourse. Their daughter was stricken with Aids after receiving a blood transfusion while being treated for injuries sustained in a car accident. Their son was born with HIV. The Chens exhibited similar symptoms and died quickly, within a year or so after they first got sick. Only the wife was diagnosed with Aids before she died. The Chen family case demonstrated the three best-known pathways through which HIV travels: blood transfusion, sexual intercourse and birth. However,

even those who were healthy could still succumb to unethical medical practice.

In October 1997, Li, a recent graduate from a famous university, was assigned to a state work unit. There he shared a dormitory room with another single man, who was sloppy with personal hygiene. Ever health-conscious, Li decided to get a physical exam at a local government hospital, which advertised in a paper. When he was 'diagnosed' with three types of STD, he was as puzzled as he was embarrassed. He contemplated taking his own life.

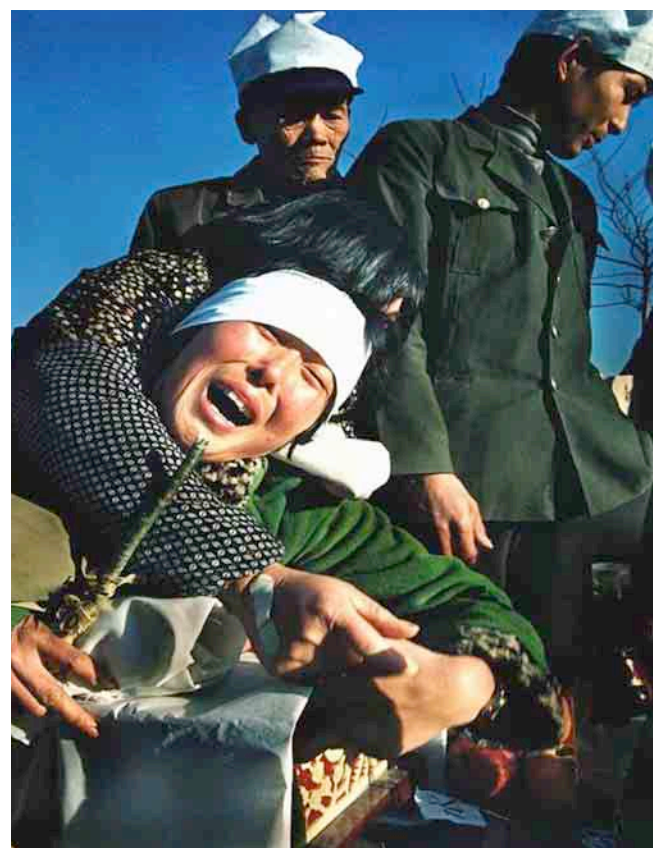
Li's father took him to the provincial hospital for a second opinion. The doctors there found him to be perfectly healthy with no disease whatsoever. It turned out that the government hospital had contracted out its STD diagnostic division and Li had fallen victim to the quacks who staffed it. They nearly ruined his life.

In January 1998, I presented media reports on Li's case directly to the [Henan] provincial head, Ma Zhongchen. I urged him to crack down on the phony physicians who profit at the expense of public health. Ma reacted promptly. By the end of March, he had kicked off a campaign to flush all charlatans and fake medicines out of the province. This opened up a can of worms.

I began receiving anonymous death threats over the phone: 'You better stay out of this or we'll make you pay. We'll kill not only you but also your entire family.' The media also jumped on me, saying: 'You, old lady, are making false accusations and costing us thousands of advertising dollars.'

Even my youngest daughter was dragged into the blame game. (She lost her job at another >>

Clockwise from top left: Gao Yaojie at home in Zhengzhou, Henan province; Henan four-year-old Yao Kangkang, who had received a blood transfusion to treat an intestinal infection as an infant, died in 2003. Because of the stigma attached to Aids, he was buried by his parents in distant Xinjiang autonomous region; a widow mourns her husband, who contracted the disease by selling blood.





Left: Aids sufferers infected through blood donations wait in vain outside their provincial health centre for their medical files. Below left: Gao braves threats and harassment to visit stricken villages.



“These officials had taken bribes. They cared about their own pockets – but not human lives”

hospital in the province and went into exile in Canada.) I came to understand that these charlatans were not just a bunch of yahoos but were protected by powerful backers, including some provincial officials. These officials had taken bribes. They cared about their own pockets – but not human lives.

I know that some village doctors wrote random prescriptions for Aids patients. In Wenxi county, a doctor by the family name of Chen gave an Aids patient an intravenous injection of antibiotics. That accelerated his death. And then there were those charlatans or otherwise incompetent physicians who would use commercials, the internet and mass mailing to lure Aids victims and their families.

On October 2, 2001, Aids sufferer Ma Huanjun told me: ‘A hospital says it has Aids vaccines available. A monthly shot can protect you from the disease but each would cost several hundred dollars and I cannot afford it.’ It’s common knowledge around the world that so far, Aids is incurable and there is no vaccine. I have no idea where this hospital’s ‘Aids shots’ came from.

Sick people, especially those with Aids, are in a helpless, lonely situation. Exploiting the sick’s helplessness and desperation for a cure, these quacks pushed their ‘magic medicine’.

[Gao began to write and publish newsletters to help spread knowledge about HIV/Aids.]

Over the past few years, I have circulated my newsletter in different ways. I gave the first 10 issues out free, to provincial disease-prevention stations. From there the newsletters reached public health officials and patients’ families.

One day I decided to take the pamphlets, along with two colleagues, to a nightclub in order to reach out to the sex workers there. As soon as the women spotted us, they dodged us as if we were lepers. A few bold ones took a look at the newsletter and threw it away once they realised that it was all about Aids, howling: ‘Get out of here, old lady! What customer would come in if they saw this stuff? They would think we all are stricken with Aids.’ Then the nightclub’s boss got word of us being there. He treated us like we were his mortal enemies and kicked us out quickly.

After Lunar New Year 2000, I heard that reporters from *The New York Times* and other foreign media had asked to interview me but the provincial officials had repeatedly turned down their requests. Around the same time, I started to notice a knot of motorcyclists hanging around my housing development and keeping an eye on my apartment. One day, I boarded the bus to get to a meeting at the hospital and I saw the motorcycles following me. When I entered the hospital’s conference room, the bikers parked outside the building. Only then did it dawn on me that I was under surveillance.

A cold snap came and flurries of snow were flying. Everybody tried to stay indoors for warmth yet my young minders were leaning against their bikes, sipping bottled water and biting into stone-cold buns. I could see them clearly from the window by the fireplace inside my apartment. Every human being is born with compassion, as the old Chinese proverb goes, so I braved the snow, went downstairs and said: ‘It’s cold out here. Would you like to come up to warm yourselves and get some hot food?’

My young minders smiled, flicked the snowflakes off their coats, started their bikes and left the scene. Within 10 minutes, I could see from my window, they had come back.

As time passed I became acquainted with them. One day I asked: ‘Why are you here watching me? Who sent you?’ One of them blurted out: ‘The party leaders sent us. They’re concerned that you’re making the rounds and reporters and Aids patients are coming.’

Then I realised that the officials objected to me helping patients and raising awareness about preventing Aids. But why were they so intent on covering up the epidemic? This only steeled my resolve to visit the stricken villages and get to the bottom of it all.

On March 18, 2000, I made my first relief mission to an Aids-infected village, to deliver medicine. While there, I took some pictures of the many patients and their families. I showed them to the hospital chief [in Zhengzhou].

‘If we let people see this many Aids patients, there’d be trouble,’ she warned. She confiscated my photos and I have not seen them since. I have been told the hospital staff can’t find my photos and I should be forgiving. In my mind it’s not a matter of forgiveness: I have a right to the photos.

Certain counties within Henan had the biggest concentration of plasma buyers and sellers so I predicted that the spread of Aids would be especially rampant there.

Early on March 20, 2001, I went with two cub reporters from Shaanxi province to Weixi county, to survey the ravages of the epidemic. In the afternoon, we reached the county’s Yangzhuang township and bumped into the mayor.

Before I could inquire about the epidemic the

mayor asked his chauffeur to take me home. I didn’t go. Instead the three of us went to the nearby city of Kaifeng and spent the night there.

The next morning we rose at dawn and returned to the county. We approached a pedicab driver soliciting fares outside one of the villages. We bought him lunch and a pack of cigarettes. Once we’d established a rapport, I asked him: ‘Are there Aids patients in your village?’

‘We have a lot of sick people here,’ he said.

‘Could you show us?’ I asked. He drove us to a traditional quadrangle house, a ramshackle clinic full of Aids patients sent back from the county hospital. It was a rudimentary set-up: a pressure cooker was used to sterilise equipment; the same syringe was applied to several patients with only a new needle slapped on after each use.

A dozen patients languished on cots inside, as well as on carts parked outside the door. Some were receiving intravenous injections. Several, mostly aged between 30 and 40, looked wasted and bone-thin. They had high fevers and difficulty breathing. They vomited incessantly and suffered from chronic diarrhoea. They were being treated as if they had pneumonia.

As far as medication and compensation for victims of official corruption are concerned, these are Aids-related issues with Chinese characteristics and they call for transparency and resolution. Reticence is tantamount to a slow death.

At around 6am on November 19, 2007, I was woken by the phone. It was a man: ‘I’m an Aids patient,’ he said. ‘Yesterday, I was arrested by the local police. A few hours ago, I jumped over the fence and escaped from the detention centre.’

‘Why were you arrested?’ I asked.

Said the caller: ‘Early yesterday morning, 16 or 17 of us, all HIV carriers and Aids patients, marched to the county clinic demanding our medical records from 12 years ago. These records detail our history of blood transfusions. We waited for 10 hours in the clinic’s conference room. We were there representing the 116 Aids-stricken people from our county.’

‘The county chief showed up but wouldn’t do anything. He said that unless the central government ordered the county to acknowledge mistakes and make amends to those who got infected, county officials wouldn’t release our records.’

‘In the evening, the county’s public-safety chief and his deputy tried to move us. They yelled through the bullhorn to ask those who lingered in the clinic’s lobby to leave – or they would be tear-gassed. Police in riot gear stormed the clinic and dragged us out. Many among us were women.’”

LIFE GOES ON AS usual for Gao; she is still under surveillance and is still considered a thorn in the side of the Henan authorities.

According to Chung To, chairman of the Hong Kong-based Chi Heng Foundation – which helps mainland children affected by Aids – who was in contact with Gao a few weeks ago, she is attempting to get her blog back online and is reworking a book of letters from Aids sufferers and orphans that was once published, in a heavily censored form, on the mainland.

Like her memoir and the blog, the new version of *10,000 Letters* will probably be banned in Dr Gao’s homeland. ■

The Soul of Gao Yaojie (*Ming Pao Publishing*), in Chinese, is available at Hong Kong bookshops.