Why are some HIV/AIDS patients reluctant to receive antiviral therapy as soon as possible in China?

Yang Sun\(^1,2\), Hongzhou Lu\(^1,\ast\)

\(^1\) Department of Infectious Diseases, Shanghai Public Health Clinical Center, Fudan University, Shanghai, China; 
\(^2\) Institute of Medicine Science, Shanghai Tongji Hospital, Shanghai Tongji University School of Medicine, Shanghai, China.

*Address correspondence to:
Dr. Hongzhou Lu, Shanghai Public Health Clinical Center affiliated with Fudan University, No. 2901 Caolang Road, Jinshan District, Shanghai 201508, China.
E-mail: luhongzhou@fudan.edu.cn

Summary
In more than 20 years of medical practice, a surprising phenomenon has often occurred: some patients with acquired immunodeficiency syndrome (AIDS) decide not to go to the hospital and they do not let others know that they are suffering from the disease unless they believe that they are dying. Zhang Shan (a pseudonym) is one such patient with human immunodeficiency virus (HIV)/AIDS who was reluctant to receive antiviral therapy as soon as possible, and this paper shares Zhang's story as he related it. Clearly, there are numerous views as to why patients in China behave as Zhang did. Presented here are several reasons, including society, history, morality and ideology, family, and education. Although all of these reasons do play a role, the patient’s mindset and behavior is the most significant reason for a patient’s reluctance to seek treatment or disclose his/her status. If the individual patient’s mindset and behavior are not dealt with effectively, then HIV/AIDS can continue to spread and threaten additional lives and even the fabric of society. This paper analyzes the reasons why patients are hesitant to receive antiviral therapy, but this paper also suggests steps healthcare personnel can take to encourage patients to seek treatment. Such steps can save the lives of current patients with HIV/AIDS. In addition, sound public health measures and a rational approach to treatment are important to helping potential patients with HIV/AIDS.

Keywords: HIV/AIDS, antiviral therapy, China

Commentary
Jonathan Baker, a Physician's Assistant in the human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) program in the division of infectious diseases at the University of Pittsburgh Medical Center, Pennsylvania recently published an interesting article entitled "Stay current with options for HIV prevention" (1). In the article, Baker stated that "conventional behavioral modification strategies have had limited effect on preventing the spread of HIV, and additional options are urgently needed. Antiretroviral drugs have been approved as preexposure prophylaxis, but vaccines and topical microbicides may provide additional options." Baker's article went on to review current HIV prevention options with a focus on biomedical prevention methods.

Baker's sentiment is surely shared by other healthcare professionals who have long been fighting HIV/AIDS. However, the arduous job of prevention presents different challenges in different parts of the world.

The current article originated from a letter from a former patient with severe HIV infection who had only recently gotten his life back on track after he began to deal with his illness. His experience prompted the question of why some HIV/AIDS patients are reluctant to receive antiviral therapy as soon as possible in China.

The patient's name is Zhang Shan (a pseudonym). Zhang had returned to China from Southeast Asia in April 2010. Soon after returning, he began to feel unwell, he tired easily, he lacked energy, and he readily caught colds. Like most patients after a tortuous course, Zhang noticed trouble with his lungs and he finally went to see his doctor. On June 12, 2010, Zhang clearly and definitively tested positive for HIV. Zhang felt remorse, regret, helplessness, and despair at the time. When he was initially diagnosed, Zhang had a T lymphocyte count (CD4 T cells) of 49/μL and pulmonary tuberculosis as...
well. Specialists who considered Zhang's case felt that his prognosis was poor. After Zhang was definitely diagnosed, a treatment strategy was formulated to treat his tuberculosis first and then immediately start Zhang on antiretroviral therapy.

However, Zhang refused his doctor's advice based on his own thinking and he completely ignored doctor's instructions. Zhang did not believe that he could succumb to a virus that can only be seen under a microscope. As he reasoned, "If [the virus] is so easy for me to catch, then won't it be just as easy for my body to get rid of [the virus]? There must be a way, it just hasn't been found yet." Zhang similarly began to believe that he was capable of finding the real source (reason) of infection since doctors and scientists around the world had been unable to accurately describe the real source of HIV/AIDS. In Zhang's mind, all treatment was based on "assumptions" and thus less reliable. "Scientists and doctors are liars. I would never trust them," he said. Moreover, Zhang thought his situation was unlike the situations of others with the disease; he reasoned that his doctor may not have been able to cure him but may be could find a cure himself. Zhang wanted to find his own cure to the disease. Furthermore, Zhang was not content to take medication to control HIV/AIDS for the rest of his life. Instead, he would rather believe that doctors and scientists around the world were deceiving him rather than believing in fact. Zhang's preoccupation with curing HIV/AIDS himself brought him into conflict with personnel trying to treat him.

Zhang began to look for other possible cures for HIV/AIDS. After studying "all kinds" of AIDS-related knowledge, Zhang reached a "great conclusion" that "Western medicine is superficial and not to be trusted." "Since Western medicine can't offer me a cure, then I would rather give up on Western treatment," Zhang explained. Zhang then began to look closer at traditional Chinese medicine and he intensively studied medical information about cures for HIV/AIDS and related reports. He traveled across the country for almost a year in search of folk remedies. During that time, he met several famous "monks and Taoist priests" who claimed that they could cure him of his disease. Their treatments failed to work after almost a year, leaving Zhang penniless. Despair forced him return to this health center. Zhang's condition was grave. HIV/AIDS had taken a severe toll due to sepsis and drug allergies had almost been fatal. Zhang was infected with *Penicillium marneffei* and *Cryptococcus* and he had a T lymphocyte count (CD4 T cells) of only 8/μL. In the face of this cruel reality, Zhang lost all faith in his self-treatment. Zhang began to reconsider his original beliefs, and he realized the ridiculous and untenable nature of his previous thinking. Zhang finally discarded his old beliefs. Before Zhang's condition gradually improved and he successfully cheated death. With his condition under control, Zhang's CD4 count rose to 176/μL. Half a year later, the virus was no longer detected and his CD4 count rose to 256/μL. A year later, his CD4 count rose to 363/μL. Zhang had survived.

This true story resulted in a highly gratifying result. Using scientific and standardized antiretroviral therapy to treat HIV/AIDS patients as soon as possible is crucial. The earlier treatment begins, the better! Antiretroviral therapy might not have been the treatment strategy Zhang wanted, but the fact remains that Zhang suffered because of his own behavior. There is no denying that some older regimens of active antiretroviral therapy (AAT) are still being administered in China and other developing countries. Moreover, the adverse effects of AAT usually result in opportunistic infections and complications. According to the 2012 China AIDS Response Progress Report by UNAIDS, China has a large population of people living with HIV/AIDS (PLHIV). Although AAT is the primary treatment for many potential sources of infection, traditional Chinese medicine has also been widely used as a complement to mitigate the adverse effects of AAT in China and other countries. Due to social beliefs and technical limitations, there is still no quantifiable standard governing the availability and toxicity of AAT. The low price of traditional Chinese medicines is the sole reason why they are used by a significant number of PLHIV in China (6). More clinical studies should be done to analyze traditional Chinese medicines in-depth. Drug administrators and policymakers should help PLHIV.

Medicine has made great strides in the development of HIV/AIDS antiretroviral therapies. Recent studies had highlighted the importance of eradicating HIV and curing AIDS. New views on antiretroviral therapies and multidisciplinary approaches to eradicating and curing HIV/AIDS have been described. One approach involves memory CD4 T-cells and seeks to utilize their stem cell-like properties to eliminate the viral reservoir in the hopes of achieving an AIDS-free world. Mounting research into stem cells has indicated that memory CD4 T-cells have stem cell-like properties and it has revealed their decisive role in antiretroviral therapies in the battle of modern medicine against HIV infection. This is in spite of the fact that both innate and adaptive immunities are indispensable and that numerous cells participate in anti-HIV immunity and antiretroviral therapy. Memory CD4 T-cells are nonetheless key cells that can organize all immune actions against HIV during antiretroviral therapy. Chinese clinicians and public health professionals were aware of and versed in advances made over the past few decades, but they view the current state of antiretroviral therapy and future challenges from a different perspective. The daunting task is to transform or change traditional or inculcated beliefs of potential AIDS patients so that they are open to antiretroviral therapy, which is a product of modern science, to help their plight.
The question is how to encourage patients to return to the hospital and receive antiretroviral therapy. Public health education will enhance the awareness of potential AIDS patients. Potential patients, however, face disparities in the current healthcare system. This is true in China as well as in other parts of Asia. Healthcare professionals are still in the learning phase in terms of guiding potential patients as they try to understand how to deal with affected individuals on a social level and as they try to bridge the gaps that cause disparities in access to care and effectiveness of treatment (9,10).

Potential patients should be reminded of the words of Sir Isaac Newton: "If I have seen further, it is by standing on the shoulders of giants." Our clinicians, public health professionals, and educators/researchers have very important roles to play in eliminating disparities in behavior and mindset. Identifying challenges and barriers to healthcare in underserved communities is the first step in eliminating all disparities and providing tailored healthcare including antiretroviral therapy. Recently, the University of North Texas Health Science Center has actively worked to combat the problem of health disparities in Texas by promoting research, education, and training activities for underrepresented minorities (i.e. potential patients) (11). Clinicians, researchers, community workers, and other public health professionals noted how certain conditions disproportionally affect various minority populations. If such efforts were to be implemented in China, then there would be far fewer Zhangs.

References


(Received February 9, 2014; Revised April 29, 2014; Accepted May 10, 2014)