

Living for the Community, Significance and the Past are not the Same--The Inner Thoughts of Persons  
Infected with HIV

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1. Due to the widespread bias toward AIDS in society, caring for people infected with HIV and AIDS has become an important conception in the prevention of AIDS. In these in-depth interviews in this area, the author heard some differing voices.

2. "Excessive care and concern marginalizes this group even more; only acceptance, equality, and respect can truly dispel the bias within society. If we include all infected persons and treat them equally, without discrimination, each taking up his or her own share of responsibility, then this disease should not be so terrible." Australia's senior expert Dr. Gao Yuan caused this reporter to reconsider. How do those infected view life? What kind of "love and concern" do they need? Coexisting within a social environment, how should we treat those with HIV and AIDS? With these questions, today this reporter interviewed two infected persons and two experts. Let us follow in the reporter's footsteps, enter their lives, and listen attentively to the words spoken from their hearts...

Infected person #1: Approach life with kindness, enjoy each day.

3. Wang Yang was surprised that the media found him so quickly, because in March of last year, since testing positive for HIV, he has been very careful, and even his close friends do not know the result. Before agreeing to be interviewed, he asked himself, "Do I really want to reveal my true feelings? If I speak, to what extent?" Once the subject was opened up, however, all his apprehensions disappeared. Wang Yang believes that infected persons especially should enhance people's awareness, strengthen the public's knowledge, regard themselves as members of society, take up their own responsibilities, and only then can societal discrimination truly be reduced.

4. In March of last year, after I learned that I was infected with HIV, In my heart I felt wounded, I felt that at heart I am good-natured, from never having done anything to harm another person, in fact having done many things to contribute to public welfare, I have to face this outcome. It was very painful. But this period of time was fairly short.

5. I was once in a serious car accident, and, facing death, I thought how in life there are still many things I want to do that I haven't done, and it was a hard time. After I recovered, I felt I could not go on living the way I had before, so I resigned from my job and stayed with my parents for over a year. Afterwards I went to Yunnan, wanting to do some things that I always wanted to do and which were meaningful. In August of last year, I arrived at an organization and became a volunteer, and in the process of helping others, I came to enjoy the happiness that the work brought to me.

6. Facing death again, I began anew to think about the question of life. This time I did not feel afraid, because I still have time. I can still plan the last portion of my life well, and live out my plan. At the same time I can receive treatment to extend my life. the length of life is not important, what is important is living each day well.

7. As a member of society, each person has a duty to himself. I understand that my responsibility toward my own life is also my responsibility to society. AIDS is a communicable disease, so most important is that I do not transmit it. At the same time I must have a positive attitude. All things have a process of being accepted. When our thought process is normal, when we have a good environment, we will not be of a mind to retaliate against others, or against society. If we have a healthy circle of people who can provide this kind of safe environment, then they themselves will be safe. Harmony is something that must be created and sustained by each person.

8. I did work in the community for over a year, and now I am still a volunteer, doing some training in the area of treatment. Through this process I have found that the public's awareness in the field of AIDS

prevention has become more and more apparent, and this has given me much to think about. In particular, after I became infected, I consciously sought out knowledge, and at the same time, my desire to help other was stronger than ever before. In the course of doing this program, I found that some infected persons very much wanted to be taken care of, because they had placed themselves in a special position, waiting for someone else to come and take care of them. I do not think this right. I myself do not need special care, because this is not a relationship based on equality. Some of my friends, after learning I was infected, got along with me just the same as before, not regarding me as a special person, and this is very good. Equality is even more important than being taken care of.

9. These days, my plan is to look for work, first to support myself. I will still volunteer, but I can only do so in my spare time, because after two years I need treatment, which costs a lot of money.

10. This group is always thought of in terms of rights, but neglects its main duty, and one often sees many regrettable examples. First, if one's own mindset is not good, always believing that other people and society owes him something, that everything is the fault of others, one puts a label on himself, placing himself in opposition to society or the mainstream. Starting out with this mindset, everything is seen in the wrong way. I always start out from an amiable mindset, doing my best not to carry a label when interacting with others, not wanting to demonize myself, but wanting to construct a kind of positive, healthy atmosphere, not allowing others to misunderstand, not letting the media mislead. And this requires diligent effort on our part.

11. Among the infected persons I contacted, many share the same mindset with me. Everyone is basically friendly, very few have the notion to retaliate against society. this group of ours have sensitive and fragile hearts, we long to love and be loved, so upon learning that we were infected, our first thought was to avoid allowing our own companions and loved ones to become infected. Not only myself, but among us many were like this. Some infected persons stated unequivocally they want to find

another infected person, because only then we can love each other without any burdens on our hearts: there is one infected person, who usually lives alone, whose parents occasionally come to see him. When he learns that his parents are coming, he invariably cleans the house, especially the bathroom. In fact everyone knows that casual contact cannot spread the infection. Each time I go home to see my parents it is the same. On the last day I take everything I have used and wash and disinfect all of them. I give them very little, I don't want them to have any more pressure, I can't let them go and endure discrimination from other people. Perhaps I will never be able to tell them I am infected with AIDS. If I become ill, I will hide myself, I could not bear to have my friends come and take care of me. I'm afraid that when I am sick I will look terrible, and I worry that friends might become infected in the course of caring for me.

12. I don't know why the media became aware of me so quickly? I may cooperate to a certain degree with the media, because this group needs to express its voice, needs to have a spokesperson. Moreover, I myself have gradually accepted this role. But I worry that my family may suffer because of this, this is the main reason we as a group are not willing to reveal ourselves. But if I want to work in this field, I have to be prepared to reveal myself. This is a process, even though I dread the media.

13. Infected person #2: Let your life be full of meaning.

In August of last year when Yanzi was interviewed by this reporter, she had not been long out of the hospital. Looking back on her "rising from the dead," she is full of gratitude toward her family and doctors. After learning that she was infected with HIV, she had countless times contemplated suicide, when "to live is nevertheless to die" became the threshold she could not cross, the "prevent four, care for one" policy made her choose to go on living. Nowadays, she no longer lives only for herself, she lives for many people around her, living with difficulty yet magnificently, living in a way that has more value than before.

14. After coming out of the hospital I attended some small group activities for infected persons, and gradually entered the field of AIDS prevention. In the process of these activities I found in conversations that obstacles frequently emerged, because people were of different populations, thus their needs were not the same, and so the idea of establishing a small group for female infected persons was born. With the help of the **China Love Care and Concern Program Office**, in August of last year, while preparing to establish the group, our first **UN plan grant** in support of China's first handbook published specifically for infected women, edited and published by the infected women's group. How should infected women handle problems concerning pregnancy, breastfeeding, raising children and similar matters? how can they take care of their own family members? The handbook gives infected women practical, detailed introductions and explanations, and provides many real-life case studies, giving the reader help and encouragement.

15. I only completed middle school, so when faced with this book, written completely in English, I was terrified, but in my heart I there was a voice encouraging me: women like me who have unfortunately been infected with HIV need this book, I must do this! We organized a national conference, in which sixteen infected persons from seven provinces and cities conferred for five days. Everyone reached a consensus--to keep the knowledge section of the original text, and present the case studies completely using our own stories. Afterwards everyone separately collected and arranged all the autobiographical stories, edited them line by line, and finally in July 2006 it was published. We printed 10,000 copies and distributed them to over 300 government organizations and NGOs.

16. The second grant was capital construction funds from **Hong Kong Charitable Group**. We used these funds to rent an office (when we did the first program we had no office, we ran things and had meetings at my home), set up a reception center, we provided a place to live for infected persons coming from everywhere to Kunming for treatment. Through issuing mutual help cards, business cards and similar

methods, infected persons and family members themselves can find us, and now we have already received over 400 patients and their relatives. Our work is to care for both men and women, but we focus more on women. For example last year we did gynecological exams for infected women, but the problem is we have no way to treat them after the exams. There was one diagnosed with cervical cancer. She needs surgery, but there is no hospital to do the surgery for her, she can only use conservative treatment measures. This person is in dire straits. She is married, but her husband doesn't care about her, and doesn't take care of the family. She cares for her child by herself. All the costs for her treatment were donated by us. After a year's hard work, I feel that if we ourselves do not stand up and help them, nobody will, because only we can truly take their predicament into consideration.

17. The pressure felt by infected women is even greater, the pain they suffer is even greater. Women have the role of taking care of the family, they are at the heart of the family. After they get sick, all the pressures and responsibilities she bears become greater than those of other people. The government's policy is to treat all equally without discrimination, it cannot be directed specifically at women. I wish to work hard, to help them obtain work, solve their problems of subsistence, and also take care of their psychological needs. Women are not financially independent, they depend on men, to the point that this illness itself is the result of dependence. If we can solve their problem of subsistence, and financial independence, we can solve many problems.

18. I often face the problem of subsistence for patients and infected persons. They don't have food to eat, or if they get a meal, they don't know where the next meal will come from, so how can they get medication? They are anxious about getting food, how can they think about medicine? The nation's policy of reducing and preventing has no way of being realized in the face of these infected persons who lack the money to buy food. This is a very real problem. If we solve this problem, the number of orphans will be reduced, and the burden to the country and society will be reduced.

19. I detest the methods of those who regard us as tools to be arranged or used for their own benefit.

We emphatically are not using this identification of ours to coerce the government into giving us special treatment, in fact, we only want the relevant departments to know that we are not the same as other people, able to pay attention to our uniqueness. Our purpose in doing this is that we want to help the government see those problems that they have not yet seen or imagined.

20. At the beginning, the doctor saved my life; if there had not been free medicine, I may not have lived until today. Many who were with me together in the hospital have already died, because they did not understand the policy. Therefore, to understand the policy is also to take responsibility for oneself. To understand the policy, the patient's condition and progress, to seek the opportunity for resources and treatment, obtaining help, all these are the means of taking responsibility.

21. These days I am very busy, I seldom go home, I study and take many trips. I cannot manage my family, and I often sleep at the office. I live for many others. The significance of my living, the meaning of life, is not the same as it was in the past.

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