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# HIV/AIDS-related Discrimination in Shanxi Rural Areas of China[1]

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**Objective** In order to explore the features of discrimination against people with HIV/AIDS in rural areas, a community-based intervention was carried out in two pilot communities of X County of Shanxi Province from September 2002 to October 2003. **Methods** Data were collected using qualitative methods (in-depth interview and focus group discussion) and anonymously structured questionnaires. **Results** (1) Severe discrimination against people infected with HIV/AIDS was revealed in the target communities. However, the response to HIV/AIDS was different in each community. (2) People were reluctant to disclose their HIV status or get tested for HIV, which endangered their sexual partners to contract HIV through unprotected sexual intercourses. (3) Attitudes towards people infected with HIV/AIDS varied. (4) Public education promoted a better understanding of HIV/AIDS which in turn improved community attitudes and behaviors towards people with HIV/AIDS. **Conclusion** HIV/AIDS-related discrimination undermines both individuals' and communities' responses to HIV/AIDS and may be a serious obstacle towards effective HIV/AIDS prevention and control.

**Key words**: HIV/AIDS; Discrimination; Rural area; Intervention

## INTRODUCTION

It has been universally recognized that there are three phases for HIV/AIDS epidemic in any society: epidemic of HIV, epidemic of AIDS, and epidemic of stigma, discrimination, and blame as well as collective denial which makes the tackling of the problem more difficult[1]. By the end of 2002, it was officially reported in China that there was a cumulative 40560 cases of HIV, including 2639 cases of full-blown AIDS, and 1047 deaths. However, it is estimated that over 1 million people have already been infected with HIV[2]. Although there has been a significant amount of researches carried out on the HIV/AIDS epidemic in China, few studies on HIV/AIDS-related stigma and discrimination are available.

X County in Shanxi Province, is on the border of Shanxi and Henan. It has an area of 1353 square kilometers with a population of 350 000. Although agriculture has been thriving in recent years, the overall economy remains under developed. X county is considered a national poor county with a per capita average income of 1712 RMB per year. In the early

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1990s many farmers in one of the two pilot communities (with about 1000 residents) sold their blood. Poverty, commercial blood donation and HIV/AIDS constitute a vicious circle with poverty resulting in the sale of blood and plasma, which in turn triggers fresh HIV infections and exacerbats poverty. There have been 13 reported cases of HIV infection in one of the targeted communities, which accounted for 46.4% of the HIV/AIDS cases in X County. Some young and middle-aged villagers who sold blood and plasma, died without clear causes in 2000 and the first person with HIV was identified in the same year. This caused panic in the village and neighboring villages. This also prompted discrimination against people diagnosed with or suspected of being HIV positive as well as their family members. Discrimination from neighboring villages was more obvious, and this was expressed in actions including denial of residents from affected villages to take public transportation, breaking of business contracts, retraction of marital arrangements, teachers refusing to teach in affected villages and people refusing to visit relatives in affected villages. These activities forced the village leaders to deny the existence of HIV positive persons in the village and refused any HIV-related publicity by health department to avoid more possible troubles.

In order to study the discrimination against people living with HIV/AIDS (PLWHA), the above county was chosen as the pilot community. Another matched community was also chosen, which was close to the first village and had a similar economic profile and population size, but had fewer blood donors and no reported HIV positive person. This permitted the comparison of the intervention between the target community which had cases of HIV and the matched community which had none. The study involved a community-based intervention to reduce discrimination against PLWHA which was carried out in the two pilot communities from September 2002 to October 2003. The primary objective of the project was to reduce community apprehension about AIDS and subsequent discrimination against HIV positive people in order to build a better social environment for HIV/AIDS prevention and care through health education, promotion and support.

## METHODS

The intervention included: (1) to establish an activity center for people with HIV/AIDS; (2) to develop training and information, education, and communication material, such as information sheets and pamphlets, a VCD, exhibition and performance material; (3) to provide care and support, as well as free condoms for PLWHA.

In-depth interviews and focus group discussions were conducted with 33 participants (including PLWHA, their family members, leaders of community, medical workers, teachers and villagers). The anonymously structured questionnaire was administered to 18-65 years old villagers both pre- and post-intervention activities. Data were collected in November 2002 (baseline survey) and October 2003 (evaluation survey), respectively. The questionnaire included questions on demographic characteristics, living status, commercial blood donation, knowledge of HIV/AIDS, HIV testing, attitudes and behavior towards PLWHA, sources of knowledge and needs, as well as condom use. Researchers received training and followed the principle of informed consent. Of the 505 individuals enrolled in the survey until completion, 97% (490) had valid baseline data and 99.6% (456/458) were eligible for evaluation. Data were analysed using SPSS 11.0 and *t*-test and $\chi^2$ were used. Attention was paid to significant differences at the 5% level or less.

## RESULTS

### *Demographic Characteristics*

The mean age of participants was 39.9 (±11.8) years (baseline survey) and 40.2 (±11.3) years (evaluation survey), respectively ($t$=0.23, $P$=0.63). No differences were found between these two surveys. The sex ratio was nearly 1:1 with slightly more female respondents than males. The majority of participants completed junior high school (about 50%), next to primary education and senior high school. The vast majority of respondents were married (about 90%). No statistically significant differences were shown in sex, education level and marital status between the baseline and evaluation surveys.

### *Manifestation of Discrimination Against PLWHA and Those Who Were Perceived to Have HIV or AIDS*

People of different social status often had different attitudes and behaviors towards PLWHA and those who were under suspicion of having HIV. Here, people suspected of HIV/AIDS referred to people who previously sold blood of plasma and accurately experienced AIDS-like symptoms (including recurring fever, diarrhoea, loss of weight, and physical inability to engage in farm work).

People from the community in which HIV/AIDS was still absent, viewed villagers from the HIV positive community as potential risk group. They refused to keep in touch, receive students, or go to restaurants and bathhouses or marry someone who was from that community.

There were three reasons for the fear of HIV/AIDS. Firstly, they were afraid of contracting AIDS, which is a life-threatening and incurable disease. “We are afraid of infectious diseases, such as tuberculosis and hepatitis, we are even more afraid of AIDS because it is a deadly disease. Who does not? ” (leader of community, male, aged 41). This opinion represents a common response to a severe epidemic disease from lay people. Secondly, AIDS is associated with “immoral” or “improper” behavior. “Those who have multiple sexual partners and immoral behavior are vulnerable to HIV” (from a teacher, male, aged 45). Finally, fear arose from a lack of HIV/AIDS knowledge. Responders still did not believe that casual contact did not transmit HIV (Table 2), and this seemed to have great impact on attitudes and behavior towards PLWHA and those who were thought to be HIV positive.

### *Living Status of People Living With HIV/AIDS (PLWHA)*

PLWHA did not disclose their serostatus to anyone because they feared that they themselves and their children would be discriminated against. The exception to this was very close friends and those who might help them, or at least would not harm them. “(If a person discloses their HIV status to others,) It will cause a big problem. People will shun you, children will be expelled from school and have difficulty getting married.” (from a leader of village, male, aged 56). Family members of PLWHA would not reveal the secret outside the home once they learned about it. “(Cry) I dare tell no one about his serostatus. People will avoid you, will not visit you, and will not even talk with you if they know the secret.” (from a wife of a HIV positive person, aged 33). Some HIV positive persons did not inform their wives and use condoms during their sexual intercourses. “My wife does not know (I am infected with HIV)…I have sexual intercourse with her just like before…I do not use a condom.” (from a HIV positive person, male, aged 43). People with HIV/AIDS (especially AIDS patients) often suffer from some opportunistic infections. They bought some medicines or took drugs prescribed for them before rather than going to hospital because of the discrimination they would face from the medical services. Examples of this included, denial of treatment, HIV testing without consent, and breaches of confidentiality. The findings of baseline survey showed that 63 villagers sold blood at some stage. However, few of them got tested for HIV. "I have sold blood plasma before, I have thought of being tested for HIV. However, I have not enough money to do so. Moreover, it is useless, (and I would) to just take on a heavy psychological burden if I am identified as HIV positive. So it may be better not to know." (from a villager, male, aged 37). In fact, this opinion was not uncommon in the pilot communities. "I think that they (PLWHA-author) need the compassion and understanding of the society. They want to live, work and study like others without discrimination. If PLWHA can maintain a pleasant state of mind, their life expectancy may be 10 years. If they fear that others may find out their [serostatus], and become demeaned in other's eyes, they are living with high stress over a prolonged period. (Under such situations), they may died within one to two years" (from a villager, male, aged 24).

### *Effect of Intervention on Villagers*

*Knowledge of HIV/AIDS pre- and post-intervention* Four hundred and forty three (90.4%) responders heard of HIV/AIDS and 94.1% of them knew that HIV could be transmitted from person to person. The rates were slightly increased after the intervention, being 93.0% (424/456) and 94.3% (400/424), respectively (no significant differences). More people knew that AIDS could be prevented and controlled by medication after the intervention. The proportions increased from 86.1% (372/432) and 60.8% (267/439) before the intervention up to 94.7% (395/417) and 72.4% (304/420) after intervention, respectively ($P$=0.000) (Table 1).

TABLE 1

Knowledge of HIV/AIDS Pre- and Post-intervention

| Knowledge of HIV/AIDS | Awareness Before Intervention (%) ($n$=417) | Awareness After Intervention (%) ($n$=400) | $\chi^2$ | $P$ |
|---|---|---|---|---|
| Dining With or Sharing Cutlery With HIV Positive People | 71.0 | 91.2 | 55.03 | 0.000* |
| Shaking Hands With HIV Positive People | 77.7 | 93.7 | 49.55 | 0.000* |
| Having Sexual Intercourse With HIV Positive People | 95.7 | 98.3 | 5.14 | 0.077 |
| Mosquito Bites | 28.8 | 68.3 | 143.52 | 0.000* |
| Blood Transfusion From People With HIV or AIDS | 96.2 | 97.0 | 2.70 | 0.259 |
| Having a Conversation With HIV Positive People | 78.1 | 94.5 | 58.80 | 0.000* |
| Sharing Syringes With HIV Positive People | 96.1 | 96.5 | 0.22 | 0.897 |
| Taking a Shower or Swimming With People With HIV or AIDS | 48.4 | 79.1 | 124.43 | 0.000* |
| Infection From Mothers to Fetuses | 92.5 | 97.7 | 12.12 | 0.002* |

*Note*. $^*P$<0.01

*Changes in attitudes and behavior towards people living with HIV/AIDS* Before the intervention, 16.6% and 64.2% of the respondents stated that they felt "very scared" or "scared" when they had contact with PLWHA, while the proportions decreased to 5.9% and 42.6% following the intervention. 8.2% and 9.6% were "not scared" or felt "as usual" prior to the intervention and the rate increased significantly to 22.5% and 24.8% respectively. When they were asked what they would do if they knew or suspected someone was infected with HIV, 13.4% and 35.6% of responders reported that they would "stop communicating with him/her" or "alienate (them) gradually". The proportions decreased by 5.2% and 26.3% following the intervention. The proportion of participants reporting that they would behave "as usual" increased from 21.8% to 39.8%. At the beginning of the program, 70% of the participants reported to hold the opinion that HIV patients should be segregated from the public, while at the evaluation stage 37% maintained that opinion. The other changes of attitudes and behavior towards PLWHA are summarized in Table 2. During the post intervention evaluation interview, participants reported that the information, education and communication program improved villagers' knowledge about HIV/AIDS. As a consequence, villagers became less afraid of AIDS, less suspicious towards those infected with HIV/AIDS, and exhibited less avoidance behavior towards PLWHA. These behavior changes contributed to improving the living conditions of PLWHA.

*Condom use* Although the proportion of participants knowing that using condom could prevent HIV/AIDS was dramatically increased (from 57.3% to 82.1%, $\chi^2$=66.68， $P$=0.000), the number of participants who used condoms in the most recent three sexual encounters was far from being ideal. The number of participants reporting 100% condom usage increased only slightly from 2.2% (9/405) at the baseline to 6.5% (26/399) in the evaluation.

*Opinions about people with HIV infection through different routes of transmission* Responders held moral views about AIDS. A clear gradient from 'innocence' to 'guilt' has been applied to HIV/AIDS. People infected with HIV through blood transfusion, from mother to child, monogamous spousal relationships, or commercial blood donation were thought to be 'innocent' victims. While prostitutes and their clients who contracted HIV were perceived as most 'guilty', followed by drug users and homosexuals. "Poverty is the reason for selling blood,which is an action due to a lack of options, and these people deserve sympathy. Drug users and prostitutes who have contacted HIV/AIDS, in my opinion, has got what they deserve." (Villager who sold blood, male, aged 30), "People with HIV/AIDS in our village became infected with HIV through selling blood. They deserve sympathy and understanding. We should give them more help and care. However, I think those infected with HIV through drug use and promiscuous sex deserve what has happened to them" (Leader of community, male, aged 50). At the 'innocent' end of the spectrum, people infected with HIV by selling blood were considered to have some responsibility for their serostatus because it arose from their personal behavior. This moral condemnation appeared to have increased from the baseline to the evaluation (Table 3).

## DISCUSSION

HIV-AIDS-related discrimination is universal, occurring in every country and region of the world[3,4]. UNAIDS defined HIV/AIDS-related discrimination as discrimination which occurred when a distinction was made that led to a person being unfairly or unjustly treated on the basis of him or her belonging to, or being perceived to belong, to a particular group[5]. Due to its severity, its discovery initially among homosexuals and IDUs, and the use of "scare campaigns" at the beginning of the epidemic, AIDS has be come " a modern plague" and a "moral disease". People have transferred their fear and anger about AIDS to people with HIV/AIDS. HIV positive people are no longer regarded as patients, because they are backed with some immoral behaviours. This makes the marginalized population (e.g. homosexuals, drug users and sex workers, etc.) more vulnerable. People infected with HIV through "personal risk behaviour" experience triple stigma, most commonly, the stigmas of being poor, being HIV-positive and having sold blood.

HIV/AIDS-related discrimination produces a lot of adverse effects both at the level of the individuals living with HIV/AIDS and the community[6-8]. Even with the establishment of national regulations aimed at protecting the rights and confidentiality of PLWHA[9-11], many people would still not choose to find out or reveal their serostatus due to widespread negative community and family responses. HIV/AIDS related discrimination has four common consequences on PLWHA. Firstly, reluctance in disclosing one's serostatus negatively affects an individual's opportunity to receive treatment and counseling. This in turn would negatively impact on his/her knowledge and skills both in self care and in preventing transmission of the virus to others. Secondly, people who are at high risk of being infected with HIV (e.g. blood donors) are unwilling to be tested and this negatively affects their access to early identification of the virus and proper treatment. Thirdly, PLWHA who failed to disclose their HIV status to their sexual partners are at increased risk of infecting their partners with the virus through unprotected sex (either due to a failure to understand the routes of transmission or fear of raising suspicion by the sudden adoption of safe sex practice). Finally, PLWHA may miss an opportunity to receive quality treatment. Many PLWHA in their attempts to avoid discrimination resort to over-the-counter medicines rather than seeking proper medical care. On the community level, HIV-related discriminatory practice allows collective denial of HIV/AIDS epidemic, forcing the epidemic to be hidden in an underground state. This creates a false sense of security for the community from the epidemic, resulting in a collective neglect of preventive practice. All these in turn fuel the progression of the epidemic[12].

Due to the experience of "witnessing the epidemic in neighboring villages", relative to other villages, villagers in the current study had a better knowledge of HIV/AIDS[13,14]. Their awareness of the routes of HIV/AIDS transmission was high (95%) prior to intervention (Table 1). Because of this, the marginal increase in this knowledge post-intervention was not statistically significant. However, their knowledge in other areas of HIV/AIDS has increased after intervention and helped to diminish villagers' fear of AIDS and positively changed their attitudes and behavior towards the suspected people with HIV/AIDS (Table 2). However, increase in knowledge did not automatically result in change of behavior, and this was demonstrated by the very low rate of reported condom usage. The varying attitudes towards people infected with HIV clearly reflected the use of moral judgment, and this tendency to draw on moral judgment has not only failed to decrease, but also actually has increased following the intervention. This is a major setback of the intervention project. It shows a limitation in the current information, education and communication approach to HIV intervention. A point of improvement for future intervention is to lighten the moral implication of HIV in the education message, and to emphasize HIV as merely an infectious disease. Regardless of the routes of transmission, all HIV positive people are victims of the disease. This message would hopefully help to create a supportive environment for people living with HIV/AIDS.

Health education is vital to the prevention and reduction of HIV/AIDS stigmatization and discrimination. However, it is only effective to a certain extent and not the means to solve all the problems created by AIDS in the community. In order to eliminate discrimination caused by the fear of a severe disease, it is the role of the government to provide comprehensive care and support for people living with HIV/AIDS. This includes the provision of antiretroviral and antibiotic/antifungal treatment for HIV-related opportunistic infections.

TABLE 2

Comparison of the Attitudes and Behaviour Towards PLWHA Pre- and Post- intervention (*n*=867)

| Attitudes and Behaviour | Yes (%) | No (%) | Less (%) | Others (%) |
|---|---|---|---|---|
| Would You Talk With Him/her? | 29.3/43.3 | 23.4/13.3 | 38.1/30.1 | 9.3/13.3 |
| Would You Buy His/her Vegetables, Eggs? | 29.7/38.6 | 53.7/34.8 | 16.3/26.7 | 0.2/0 |
| Would You Sell Things to Him/her? | 53.9/59.2 | 31.1/18.7 | 14.8/21.4 | 0.2/0.7 |
| Would You Go to Bathhouse That He/she Manages? | 7.5/27.8 | 75.3/56.3 | 17.0/12.6 | 0.2/3.4 |
| Would You Lend Thing to Him/her? | 29.0/48.5 | 45.8/25.1 | 23.8/25.8 | 1.4/0.7 |
| Would You Borrow Things to Him/her | 13.2/38.9 | 66.8/45.7 | 19.8/14.9 | 0.2/0.5 |
| Would You Visit His/her House? | 17.9/35.7 | 53.5/37.4 | 28.3/26.7 | 0.2/0.2 |
| Would You Help Him/her? | 34.1/44.0 | 34.3/23.9 | 30.7/30.0 | 0.9/2.1 |
| Would You Have Dinner With Him/her? | 18.0/33.2 | 62.0/36.3 | 16.6/20.8 | 3.4/9.8 |
| Would You Like to Be Relatives by Marriage? | 2.1/11.8 | 90.4/85.9 | | 7.5/2.4 |
| Would You Break off an Engagement? | 76.6/80.4 | 5.7/17.2 | | 17.7/2.6 |
| Would You Like Your Children Study and Play With His/her Children | 8.3/26.1 | 81.5/52.3 | 9.7/20.6 | 0.5/1.0 |

*Note.* [a]A/B A represents the data before intervention, and B represents the data after intervention. [b]Statistical significances were found in all of 12 items between pre- and post-intervention. ($P<0.01$)

TABLE 3

Attitudes Towards PLWHA Through Different Routes of Transmission Pre- and Post- intervention (*n*=867)

| Transmission | Deserve Sympathy (%) | Do Not Deserve Sympathy (%) | Do Not Know (%) |
|---|---|---|---|
| Intravenous Drug Use | 2.7/1.2 | 90.5/97.6 | 6.8/1.2 |
| Blood Donation | 65.1/79.9 | 32.8/19.9 | 2.1/0.2 |
| Prostitutes and Their Clients | 1.6/0.5 | 95.5/99.5 | 2.9/0 |
| Homosexual | 5.2/1.2 | 80.9/90.0 | 13.9/8.8 |
| From Mother to Child | 87.8/95.3 | 9.5/1.9 | 2.7/2.8 |
| Spouse | 82.5/92.2 | 13.6/7.1 | 3.9/0.7 |
| Blood Transfusion | 94.3/99.1 | 3.4/0.7 | 2.3/0.2 |

*Note.* [a]A/B A represents the data before intervention, and B represents the data after intervention. [b]Statistical significances were found in all of 7 items between pre- and post-intervention ($P<0.01$).

In conclusion, HIV/AIDS-related discrimination deters people from coming forward to undergo HIV testing and seeking necessary information to protect themselves and others from becoming infected with HIV. Discrimination also creates a situation where physically suffering from the disease aside, PLWHA will also have to bear the huge social and psychological stress from the disease related discrimination. These stresses pose a significant obstacle to the application of preventative measures by the individual, and this in turn becomes a barrier to the control of HIV.

The World AIDS Campaign for the years 2002-2003 focused on stigma, discrimination and human rights. The main objective of the campaign was to prevent, reduce and ultimately eliminate all forms of HIV/AIDS-related stigma and discrimination[5]. As pointed out by the executive director of UNAIDS, Peter Piot, people with HIV are part of the solution, not part of the problem-they are the world's greatest untapped resource in responding to the epidemic[15]. A primary requirement is to recognize the fact that we are all living with AIDS, whether infected with or affected by it. In the context of AIDS, it is imperative that we overcome any divisions between 'them' and 'us'[16]. The only way of making progress against the epidemic is to replace shame with solidarity, and fear with hope. Replacing 'stigma' with 'collectivity', 'fear' with 'hope' is the path to HIV/AIDS control.

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