

**THE LIVES OF PEOPLE LIVING WITH HIV/AIDS IN THE DAI
COMMUNITY: A CASE STUDY IN YUNNAN, CHINA**

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ABSTRACT

HIV/AIDS is increasing rapidly in the Dai community in China where HIV/AIDS was initially found in and spread quickly among intravenous drug users. To better understand the issue of HIV/AIDS in the Dai community, the lives of people living with HIV/AIDS have been studied through socio-cultural contexts by exploring the forms and extent of the stigma and discrimination related to HIV/AIDS as well as influencing factors.

The data of this study was derived from an ethnographic study conducted in one typical Dai community in Yunnan province. By visiting and interviewing 26 families, and observing the daily life of people, the study shows that the stigma and discrimination related to HIV/AIDS underlies the pre-existing prejudices and practices toward drug abusers.

In the community, drug abusers are not only punished with written and unwritten social regulations but also rejected from “normal” life because of immoral behavior. Although drug users are stigmatized as the population suspected of being HIV/AIDS carriers, drug users who acquire HIV are not further stigmatized because of this. On the contrary, in the phase of AIDS, those patients receive great health care from relatives, family members and doctors because HIV/AIDS is perceived as less fearful than drug abuse, also because of a consciousness of the need to be kind to any patient. Under these positive conditions, internalized responses to HIV/AIDS are also likely to be positive.

In conclusion, we must note that the stigmatization may be developed or manifested differently within other socio-cultural contexts. HIV/AIDS prevention and control strategies should try to alleviate the stigmatization by taking into account pre-existing stigmatization toward high risk groups.

KEY WORDS: STIGMA AND DISCRIMINATION / PEOPLE LIVING WITH HIV/AIDS / DRUG USER / DAI PEOPLE / CHINA

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LIST OF ABBREVIATIONS

AIDS	: Acquired Immuno-Deficiency Syndrome
HIV	: Human Immunodeficiency Virus
PLHA	: People Living with HIV/AIDS
UNAIDS	: Joint United Nations Programme on HIV/AIDS
IDUs	: Intravenous Drug Users
WHO	: World Health Organization
DATC	: Drug Addiction Treatment Center
CDCP	: Centers for Disease Control and Prevention
IEC	: Information Education Communication

CHAPTER I

INTRODUCTION

1. Background and Justification

In 1981, the first case of acquired immuno-deficiency syndrome (AIDS) was reported. As a serious and fatal disease, AIDS is robbing resources and human health, even threatening human security and the development of dependents. As much a social problem as a biological and medical issue, the evidence of human immunodeficiency virus (HIV)/AIDS impact is unarguable. The AIDS epidemic has claimed 3 million people, and an estimated 5 million people were newly infected with HIV in 2003-----bringing the total to 40 million people living globally with the virus (UNAIDS and WHO, 2003).

Recently, the quality of life of people living with HIV/AIDS (PLHA) has been paid more attention because it is not only regarded as a moral requirement but also requires critical strategies for prevention. The responses of society toward PLHA are diverse and can be positive (e.g. care and support) or negative (e.g. stigma and discrimination) in different contexts.

One of the profound impacts on lives of PLHA, stigma and discrimination has been emphasized. The subject of the world AIDS Campaign for the year 2002-2003 was to focus on stigma and discrimination. Stigma and discrimination does not only refer to the matter of using the wrong words or actions, but also the disrespect of

people using negative labels to identify people who living with the illness. The HIV/AIDS-related stigma can be described as a 'process of devaluation' of people either living with or associated with HIV/AIDS. This stigma often stems from the underlying stigmatization of commercial sex and intravenous drug use – two of the primary routes of HIV infection. Discrimination follows this stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status (UNAIDSa, 2003).

Consequently, people refuse to test HIV/AIDS in public or deny their status to others because they are afraid to be stigmatized and ostracized by their loved ones, their family and their communities. This can increase the progression of the disease for themselves and also increase the risk of the spread of HIV to others. Stigma and the resulting discrimination associated with HIV/AIDS are great barriers to preventing further infections, and discourage individuals and their families from getting the adequate care, support, and treatment they need. At the same time, self-stigmatization can lead PLHA into depression, withdrawal, and feelings of worthlessness. As a result, a vicious circle is coming into being. "HIV-related stigma and discrimination remain an immense barrier to effectively fighting the most devastating epidemic humanity has ever known.....people with HIV/AIDS from minority ethnic groups are often blamed for their condition. They are viewed as causing their own misfortune rather than as individuals suffering from marginalization and inequality," according to Dr. Peter Piot, Executive Director of the Joint United Nations Programme on HIV/AIDS (UNAIDS).

In China, a developing country, the HIV/AIDS epidemic is growing fast. In the whole of China at the end of 2002, it was reported that there were 1 million HIV positive people including 160,000 deaths. However, UN estimated that there is a huge number of unreported cases and the real number is closer to 1.5 million and it is forecasted that 10 million people could be infected by 2010 unless drastic action is

taken soon (China faces up to HIV/AIDS epidemic, 2003). Most cases are identified in minority communities. In China, minorities represent less than 9% of the population, but account for more than 30% of the reported HIV/AIDS cases (UNAIDSb, 2003).

In China, intravenous drug users (IDUs) play a predominant role in the HIV epidemic. UNAIDS reported there were an estimated 2 million intravenous drug users in 2001, with 20–60% sharing needles. As a result, up to 80% of IDUs were HIV-positive in some areas (UNAIDSb, 2003). IDUs and HIV infections were first identified in Yunnan among minority groups.

Yunnan Province is located in the southwest of China. It is also a part of Mekong Sub-region bordering Myanmar in the west and Laos and Vietnam in the south. The number of HIV infections in Yunnan is one of the biggest in China annually, and the demographic and geographic characteristics of Yunnan contribute importantly to the spread of HIV. According to the reported figures, at the end of September 2001, there were 9,924 people infected with HIV in the whole Province, and most of them were IDUs from border areas.

There is stigma against sex workers, drug users and PLHA by the public and among friends and families in China. Most infected people live alone and are bitter, as most Chinese people think that HIV/AIDS is from “outside” and only “bad” people can be infected. According to the report of UNAIDS, PLHA in China suffer from severe stigma and discrimination, and often need their human rights protected. In some areas, PLHA have been prevented by law from getting married, having children, being employed or visiting public swimming pools (UNAIDS, 2003).

In 2002, a project—the Strategic Assessment to Improve the Quality of Care of the Reproductive Health Services supported by the World Health Organization (WHO)

was performed in Yunnan. Surprisingly, this project found a special ethnic group----the Dai minority was one of the more open-minded ethnic groups in Yunnan, China and does not stigmatize and discriminate against the people who live with HIV/AIDS. In contrast, they think that support and help are more important for these people than doing likewise. Orphaned children whose parents died from HIV/AIDS were cared for by the community without any discrimination.

Almost all the Dai people dwell in Yunnan province, and 60% of them live in border areas such as Xishuanbanna and Dehong, or live along the Honghe River and the Jinsha River. The total population of the Dai people is around 1 million. The Dai ethnic group has a long history with many multicultural traits which have absorbed many advantages from other ethnic groups and has been influenced by the Central Plains culture, Jiangnan culture, and Indian culture. In addition, most of the Dai people are Buddhist and their ideology has been strongly affected by Buddhism (Huang Huikun, 1997).

As mentioned above, Dehong prefecture is one of the largest settlements of the Dai people, and also one of areas of serious HIV/AIDS prevalence in Yunnan province. It is located in the southeast of Yunnan bordering Myanmar. In this prefecture, drugs users have mushroomed due to socioeconomic reforms in China among the Dai people and some of them have been infected with HIV/AIDS. A survey carried out by UNAIDS between 1992-4 in Dehong revealed that more than 30% of drug users were injecting and that between 70-80% of them were sharing intravenous syringes. Although, sharing intravenous syringes is the predominant way of HIV/AIDS transmission in this area, transmission through sexual intercourse has gradually risen recently, especially for the women whose husbands are IDUs.

Recently, the Chinese government and NGOs have paid more attention to the

control and prevention of drug abuse and HIV/AIDS in Dehong prefecture. Several intervention and research projects for HIV/AIDS have been done in this area such as peer education on HIV/AIDS conducted by the Australian Red Cross. However, few donors or researchers paid any attention to the relationship between the Dai people and HIV/AIDS and few studies talk about the stigma and discrimination related to HIV/AIDS among the Dai people.

It is impossible to fully understand the role of AIDS in or develop intervention strategies in the Dai communities unless we explore the social and cultural contexts of AIDS-related behavior. Therefore, it is necessary to understand the lives of PLHA in the Dai community based on the socio-cultural contexts. To address this issue, firstly, the existence of stigma and discrimination should be explored among PLHA. Secondly, the forms and extent of stigma and discrimination toward PLHA should be investigated deeply. Finally, the social meaning of HIV/AIDS and the impact factors should be understood. Needless to say, the results of such research will help us to understand the situation of the HIV/AIDS epidemic in this area which may be influenced by the perceptions and responses of the Dai people, and from this we can develop useful intervention programmes. Furthermore, the results of this research may contribute to the issue of stigma and discrimination in relation to HIV/AIDS.

2. Objectives

To understand the lives of PLHA in the Dai community, this research aims:

- To understand the existence of stigma and discrimination in relation to HIV/AIDS in the Dai community;
- To explore the forms and extent of stigma and discrimination related to HIV/AIDS in the Dai community;
- To explore the social, cultural and other factors which shape or influence the

stigma and discrimination related to HIV/AIDS in the Dai community.

3. Research Questions

3.1 How do PLHA live in the Dai community?

- Are they stigmatized and discriminated against by other community members?
- What are the forms and extent of stigma and discrimination?

3.2 Why do stigma and discrimination exist or not exist in the Dai community?

- How does the Dai culture influence the stigma and discrimination?
- How do social and other factors contribute to the stigma and discrimination?
- How do the epidemic's situation and the HIV/AIDS campaign impact on the stigma and discrimination?

CHAPTER II

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

This chapter is divided into three parts. First of all, the first part provides a description of stigma and discrimination, including the “general definition of stigma and discrimination” and “stigma and discrimination in relation to HIV/AIDS.” The stigma and discrimination related to HIV/AIDS is emphasized in this part. I have reviewed the definition, sources, manifestations and phases as well as the consequences of stigma and discrimination related to HIV/AIDS. The second part of this chapter reviews factors that may shape or influence stigma and discrimination related behavior. This part shows that cultural beliefs, religion, social relationships in terms of gender, power and economic status are the main factors that contribute to stigma and discrimination. We can also see that the media, health education and intervention programmes may influence the response toward HIV/AIDS. Based on this literature review, the third part---the conceptual framework was developed for this study, but was modified according to the research findings.

1. Stigma and Discrimination

1.1 General Definition of Stigma and Discrimination

Based on the theory of symbolic interactionism, a person who has been identified or labeled as deviant would receive relatively negative treatment from others and develop a bad reputation or deviant identity (Robert H. Lauer, Warren H. Handel, 1977). Stigma can be defined as feelings of dissatisfaction that people have about

particular illnesses or ways of behaving.

Erving Goffman argued that the individual whose presented identity has been discredited may feel nonplussed while the others present may feel hostile. Thus, stigma may occur when an individual becomes discredited in the eyes of others (1959). According to Roy Porter, “Stigma is thus negotiable, yet it is integral to the heart-felt urge to find meaning in sickness” (1998). Some researchers also describe stigma as a feeling of being negatively differentiated toward owing to a particular condition or state (Julic Arboleda-Florez, 2003).

Stigma is also a process of devaluation and is related to negative stereotyping and prejudicial attitudes. Dovidio describes stigma as social construction influenced by cultural, historical, and situational factors (Dovidio, Major, & Crocker, 2000). A stigmatized person is perceived to be different from normative expectations because of one or more undesirable characteristics, which lead to a devalued or deviant identity in certain social contexts (Dovidio et al., 2000).

Simply speaking, discrimination is the practice of treating somebody or a particular group in society less fairly than others. Stigma focuses on such feelings as shame and guilt. This leads people to modify their behavior according to such negative feelings. Therefore, discrimination can be regarded as the consequence of stigma. “Discrimination occurs when a distinction is made against a person that results in his or her being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong, to a particular group”(Peter Aggleton and Richard Parker, 2002).

1.2 Stigma and Discrimination in Relation to HIV/AIDS

1.2.1 What are the stigma and discrimination related to HIV/AIDS?

According to UNAIDS Fact sheets, HIV/AIDS-related stigma can be described as the ‘process of devaluation’ of people either living with or associated with HIV/AIDS. This stigma often derives from the underlying stigmatization of sex and intravenous drug use – two of the primary routes of HIV infection. Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status (UNAIDSa, 2003). Actually, stigma and discrimination are closely linked but discrimination is more easily identified because it often includes public restrictions and punishment (Joanna Busza, 1999).

Generally, there are different levels of ignorance, denial, fear and intolerance toward the disease in most communities because HIV/AIDS is linked to “deviant behavior”, such as homosexuality, drug use and death. PLHA are often blamed or perceived as doing something wrong (Peter Aggleton and Richard Parker, 2002). For example, if a man is infected with HIV, people will think he must be homosexual, or bisexual, or has had sex with prostitutes. For women, it will be linked to sex workers. Therefore, PLHA often carry a double stigma: the disease itself and the possibility of “deviant behaviour” (Peter M. Nardi, 1990).

Some people think that stigma creates, and is reinforced by the structure of society through norms and values. This causes some groups to be devalued and ashamed, and others to feel that they are superior. Discrimination occurs when negative thoughts lead people or institutions to treat PLHA unfairly and unjustly (Discrimination Against People With HIV/AIDS Still an Issue in Australia, 2004).

Stigma and discrimination can also be spread and reinforced by the ideology of HIV/AIDS. UNAIDS pointed out that a series of powerful metaphors were mobilized which serve to reinforce and legitimate stigmatization such as HIV/AIDS as death, as punishment, as a crime, as war, as horror and as “otherness” Such metaphors provide a powerful basis for both stigmatizing and discriminatory responses (Peter Aggleton, 2001).

1.2.2 What are the sources of stigma and discrimination?

Richard Parker and Peter Aggleton identify the four sources of stigma and discrimination as: 1) sexuality: sexual transmission is the main pattern of HIV infection routes in most areas of the world. The first infected populations are those whose sexual practices or identities are different from the “norm.” Thus, pre-existing and social constructed ideologies of sexuality inspire or reinforce the stigma associated with sexually transmitted diseases. 2) gender: female and male behaviors may be perceived and treated differently based on the stereotypes of gender. The impact of HIV/AIDS-related stigma and discrimination on women reinforces pre-existing economic, educational, cultural, and social disadvantages and unequal access to information and services. 3) race and ethnicity: racial and ethnic stigma and discrimination increase the vulnerability of minority population groups to HIV/AIDS, which in turn reinforce the stigma and discrimination. 4) class: pre-existing social inequalities and stigmatization of the poor, homeless, landless, and jobless increase the vulnerability of those people (Richard Parker and Peter Aggleton, 2002).

1.2.3 How are the stigmas and discrimination manifested?

Stigmas and discrimination related to HIV/AIDS may take different forms and occur everywhere including the family, community, schools, and workplace, even

legal and health care settings. People can be discriminated against by both strangers and acquaintances. For example, doctors or nurses may refuse to provide services to a person living with HIV/AIDS; employers may discharge staff who have been infected; or families/communities may reject those living with, or believed to be living with, HIV/AIDS.

Virginia Bond pointed out that some free medical schemes for sex workers make them feel “special”, and very common forms of stigma can be gossip, verbal abuse and name calling (Virginia Bond, Elaine Chase, 2002). In South Africa, social isolation is a major manifestation of stigma. People refuse to discuss their disease and children who are affected with HIV are ostracized by their peers (Horizons, 2002).

One survey among patients in a dental office revealed that 74.9% respondents of 490 were concerned with HIV/AIDS transmission in the dental office. Only 21.2% intended to continue treatment at a dental office where HIV/AIDS patients were treated, and only 20% would like further treatment if the dentist was HIV positive (Maria Esther Irigoyen-Camacho, 2002).

The manifestations of stigma and discrimination related to HIV/AIDS can be concluded as follows based on the different contexts (Peter Aggleton, 2001; Richard Parker and Peter Aggleton, 2002).

1) Policy and legal contexts: at this level, HIV/AIDS related stigma and discrimination normally manifest themselves in the form of laws, policies, and administrative procedures such as forced screening and testing, compulsory notification of AIDS cases, prohibition of people with HIV/AIDS from certain occupations, restrictions to the right to anonymity, and medical examination, isolation, detention and compulsory treatment of infected persons.

2) Institutional contexts: this level refers to the stigma and discrimination that take place in different social institutions, including education, employment, the health care system, religion, HIV/AIDS programmes and the media.

3) Community contexts: different communities may make different responses to HIV/AIDS because local cultural beliefs and explanations for the disease and the causes of the disease may contribute to the stigma and discrimination. It is commonly manifested in the form of blame, punishment, violence and even murder.

4) Family contexts: in fact, the family is a shelter or source of help and support for the individual. However, for HIV/AIDS, negative responses still occur and appear in different forms such as blame, rejection, and the loss of children and the home.

5) Individual contexts: the fear of stigma and discrimination may lead infected people to isolate themselves from society, or give up to seeking support and treatment and induce self-stigmatization. Sometimes, they will take radical actions in society such as deliberately having sex without condoms, or hiding their status from partners.

1.2.4 How many phases of stigma and discrimination are there?

Some researchers have pointed out that process of HIV/AIDS related stigma and discrimination can be divided into four phases: 1) at risk: pre-stigma and the well-worried; 2) diagnosis: confronting an altered identity; 3) latent: living between illness and health; and 4) manifest: the passage to social and physical death (Angelo A. Alonzo, Nancy R. Reynolds, 1995).

1.2.5 What are the consequences of being stigmatized and discriminated against?

“HIV/AIDS-related stigmatization and discrimination threaten the effectiveness of people to react to PLHA in ways that can have negative effects on individuals, families, and communities” (Population Council, 2002).

Needless to say, HIV/AIDS related stigma and discrimination may have serious consequences for individuals, families and communities. It can lead to depression, lack of self-esteem and despair for PLHA. Not only are PLHA stigmatized but also other family members suffer from stigma and discrimination, even orphaned children. It is an obstacle to further prevention and an activator for the epidemic. Fear and prejudice may increase the risk of infection or lead to ignoring the possibility of infection.

In contrast, the needs of PLHA are far beyond drugs and health care. Social and psychological support from the family, and lovers are more important to cope with the disease. Care and support combat the virus directly and improve health and the chance of survival. Since 1997, UNAIDS has advocated that communities and other stakeholders should be involved in developing standards for HIV-related care and support (UNAIDS, 2000).

2. Factors Influencing Stigma and Discrimination Related Behaviors

As a matter of fact, stigma and discrimination in relation to illness have been studied in different areas, such as mental illness, epilepsy and leprosy (Pimpawun Boonmongkon, 1994; Martha J. Morrell, 2002; Ria Reis, Harry Meinard, 2002; Jennifer Boyd Ritsher, 2003). Recently, stigmas and discrimination as negative responses to HIV/AIDS have been studied in different societies. The effects of differ from one community to another, because they result from the varying impacts of the

epidemic on different communities in terms of the nature of prevailing socio-cultural and economic conditions. Here, comparing and integrating a series of studies, and the major impact factors/causes which may shape and influence the responses of the community towards HIV/AIDS can be identified and concluded as follows:

2.1 Knowledge and Fears

From a medical perspective, the term HIV refers to the human immunodeficiency virus. The illness caused by this virus is named AIDS. This virus is passed from one person to another through body fluids, including blood, semen, vaginal fluid, breast milk and other body fluids containing blood. Therefore, the spread of HIV can occur when these body fluids come in contact with tissues such as the vagina, anus, mouth, or eyes or with a break in the skin, e.g. from a cut or puncture by a needle. The most common ways of transmission include sexual contact, needle sharing, and transmission from infected mothers to their newborns during pregnancy, the delivery process or breast-feeding. People with HIV are called HIV infected. Most of these people will develop AIDS as a result of their HIV infection (How is HIV spread /transmitted, 2004).

On the one hand, the accuracy of knowledge and information on diseases received by people is directly related to their attitudes and responses. On the other hand, the received information and knowledge is modified and interpreted in the light of people's current knowledge, attitudes and beliefs of health and illness in terms of local history and traditions. This dynamic process impacts responses at all levels of society.

One research project revealed that most people know how HIV is transmitted, but more detailed knowledge is incorrect or missing altogether which combines with the

fear of death from HIV to evoke avoidance of those living with HIV (Laura Nyblade, etc, 2003). Douglas also identified that fears, bigotry and misinformation are primary sources of HIV/AIDS related discrimination (1990). Lack of understanding or knowledge of HIV/AIDS, myths about how HIV is transmitted, and irresponsible media reporting on the epidemic can lead people to fear the illness and evoke stigma and discrimination against infected people (Peter Aggleton and Richard Parker, 2002). Another research project performed in India revealed that many factors underpin the forms of stigmatization and discrimination and many of these relate to the very real fear of HIV/AIDS that exists among the general public and professionals in health care. The sources of these fears are a lack of knowledge, as well as the irresponsible reporting of the national and local media (Peter Aggleton, 2000).

Needless to say, health professionals and the media are the main channels for health education and the diffusion of information. Therefore, the methods of education and diffusion, the language and the accuracy of the information that health professionals and media is adopted can not be ignored. Laura Nyblade, also states that the media is a powerful tool by virtue of its tremendous reach and ability to influence people's opinions and actions toward HIV/AIDS (2003).

In addition, misunderstandings may be influenced by cultural beliefs because illnesses are cultural phenomena and social constructions. The meanings of illnesses were shaped by people's living and working conditions, including gender, lifestyles, and specific customs influenced by the cultural and social context. The meaning of HIV/AIDS can be different from time to time or space to space. Sometimes, it can also be constructed or reinforced by the media, language and religion.

During the first years of the HIV/AIDS epidemic, the disease was considered a "gay" disease because the first cases were found among homosexuals (Rose Weitz,

1992). In Rwanda, people see HIV/AIDS as being of American and European origin and as having originated among gay men or IDUs (Christopher C. Taylor, 1990). In some rural areas, HIV/AIDS was considered a “City sickness” (Paul Farmer, 1990). One research project performed in Haiti revealed that HIV/AIDS was regarded as a “new disease” and “God’s illness”. It may be transmitted by contact with “dirty” blood which will cause “skin infections”, “drying up”, “diarrhea”, and “tuberculosis” (Paul Farmer, 1994). UNAIDS made strenuous criticism of the descriptions of HIV/AIDS as a “women’s disease”, a “junkies disease”, a “Black disease”, or a “gay plague” by the media and televisions (Peter Aggleton and Richard Parker, 2002).

The perceptions of the illness will cause different responses to the illness or sick people HIV/AIDS is a unique and fatal disease that is unlike cancer, heart disease or other illnesses, so how people define and understand HIV/AIDS may contribute to their responses to the illness.

2.2 Culture, Power and Difference in the Community

People’s ways of thinking, feeling and acting may be said to be influenced by (1) the cultural values and norms shared by members of a society and (2) the networks of social relationships that locate people and groups with respect to each other (Blau 1960).

As can be seen from the language, diet, dress, sexuality, art, and music; the customs of human beings, culture is the major way in which human beings adapt to their environments. It is necessary for the survival and existence of human beings and influences many aspects of people’s daily lives including knowledge, thought, perceptions, values, feelings, behaviors, and responses.

Pre-existing local cultural practices and beliefs are important impact factors of stigma and discrimination in relation to the illness. In Thailand, the ideology of gentleness can be used to explain the apparent lack of strong ostracism in people's interactions with patients (Pimpawun Boonmongkon, 1994). In Zambia, people believe that if somebody is bewitched, he/she does not carry the shame that accompanies HIV/AIDS. Therefore, PLHA who are "bewitched" receive more acceptance and better treatment (Virginia Bond, Elaine Chase, 2002).

In addition, "these cultural beliefs frequently establish categories of people or types of behavior that are likely to be stigmatized (e.g. sexually "promiscuous" individuals, sex workers, drug users and homosexuals). The advent of HIV/AIDS frequently reinforces these already existing types of stigma, imbuing them with new and potent legitimacy" claimed by Peter Aggleton (2000). Virginia Bond also mentioned women in clubs were labelled for their love of money, selling their bodies and spreading HIV/AIDS (2002).

Cultural beliefs differ from community to community, and from group to group. This depends on what each community has received from their ancestors as a heritage (Godfred Paul, 1996). From time to time, some aspects of culture may be maintained, but some aspects can also be changed. HIV/AIDS is a unique disease, so completely interacting between culture and responses to the disease. Culturally determined values influence individual's perception of AIDS and HIV/AIDS can also change many aspects of culture.

For example, some researchers point out that elderly people with HIV/AIDS are more likely to be interpreted as part of the normal ageing process because people think they are not sexually active, they do not spread the disease to others (Herber Muyinda, J. Seeley, 1997). However, some researchers also found that many older people who

had been infected were facing innumerable problems due to rejection by their families. Because HIV infection is considered for younger people, society condemns the behavior of older people and their indulgence (Godfrde Paul, 1996).

Stigma is a complicated issue that has deep roots in social relationships such as gender, race, ethnicity and economic class (Editorials, 2002). Pimpawun Boonmongkon also pointed out in her study that we should take gender, class and power relationships into account, if we study stigma related illness (1994). Sometimes, these relationships mix together to place sick people in an inferior status and suffering from stigma and discrimination.

Social relationships can stem from social stratification which ranks the individuals into appropriate social classes in terms of the degree of desirable qualities that people have. The degree of desirable qualities are different in each society and can vary, such as education, income, wealth, gender, race and even the number of wives or the number of cattle a family owns (Bruce J. Cohen, Terri L. Orbuch, 1990). According to the social stratification in a community, the rewards of society such as income, power, and status are unequally distributed among the members of that society in order to ensure that the most important positions are filled by the most qualified people available. People who are in the upper classes control the distribution of rewards, even social norms and values, and those people are looking down at the bulk of the population, while people with lower social classes are looking up.

Firstly, social relationships may determine whether stigma and discrimination exist in a community. For example, if community members are homogeneous with more equal power among them, they may not blame and discriminate against each other.

Secondly, there are different degrees of stigma and discrimination in terms of people's position and power relationships, such as rich or poor, landlord or landless, employer or employee, adult or child, and majority or minority. Pimpawun Boonmongkon mentioned that the economic class of people plays a role in determining the degree of stigmatization. For patients who are wealthy, stigma and discrimination do not completely limit their opportunities to achieve their goals. The poor are already socially marginalized by their status (1994). Virginia Bond also revealed that poor women and single women with HIV/AIDS were especially despised (2002).

Laura Nyblade in her study also identified that people believe that poor people are forced to engage in risky behavior, so the poor are blamed less for their infections than the rich. However, at the same time, the poor are not able to access the resources to hide a HIV-positive status and non-stigmatizing care so they face greater stigma than the rich (2003). In addition, if we would like to understand the effect of AIDS on minority people, we should understand their social status because normally, minority people are already stigmatized by poverty, race, and gender. Dooley Worth found that minority women with HIV/AIDS such as black women suffer more from stigma in the USA (Dooley Worth, 1990).

Thirdly, social relationships between different genders act in a special role in stigma and discrimination. Gender is a social construction and a human product. Although there are differences in different societies, gender defines the differentiated roles and norms for men and women based on hierarchical values and sets the boundaries for the construction of gender identities. Therefore, it regulates and impacts on the attitudes and responses in society for men and women.

Long-standing ideologies of gender relationships result in women being blamed frequently for infection or behavior. Female IDUs are perceived as being more “deviant” and are more negatively stereotyped than male IDUs (Dooley Worth, 1990). In India, researchers found that blame for the transmission of sexually transmitted infections was often placed on women— either directly or indirectly. While seropositive men may be offered support and care, the same is unlikely to be true for women. In Uganda, women in particular were often blamed for the death of a husband (Peter Aggleton, 2000).

On the contrary, one research project claimed that men with HIV/AIDS were also treated unequally. Health professionals paid little attention to men’s paternal role and did not provide information or knowledge about treatment options that would protect infants (Vera Paiva, Elvira Ventura, 2003).

Finally, HIV/AIDS in relation to stigma and discrimination plays an important role in producing and reproducing the stratification of gender and power. Some groups will be devalued, and existing social inequalities will be reinforced by stigma and discrimination (Peter Aggleton and Richard Parker, 2003).

2.3 Religion

In many communities, religion as a part of culture strongly influences and constructs people’s beliefs and behaviors. It’s role can not be ignored, if we would like to study stigma and discrimination in relation to HIV/AIDS, it is also necessary to study the diffusion of information, and construction of perceptions and responses to the diseases. There are different beliefs or responses to HIV/AIDS among the various religions, and even in the same religion.

Michael D. Quam revealed that in some Christian sects, AIDS is seen as an example of the biblical admonition that “the wages of sin are death” (1990). Victims of the disease were regarded as being personally guiltless in terms of the Judeo-Christian tradition. Therefore, sick people were seen as being guilty of religious or social deviancy, or social “otherness” (Dooley Worth, 1990). However, in some areas of Zambia, according to one of the Christian principles—love your neighbor as yourself—people do not stigmatize and discriminate against people with illnesses, even with HIV/AIDS. Many churches play a key role in praying and caring for the sick (Virginia Bond, Elaine Chase, 2002).

Laura Nyblade pointed out in her study that religious beliefs contribute to stigma by considering HIV as a punishment from God for sexual sins. However, on the other hand, religion-based institutions provide care and support to PLHA and diffuse the basic precepts for not stigmatizing PLHA (2003).

One research project on HIV/AIDS and Buddhism was done in Thailand. As can be seen from the findings of this research, some monks consider AIDS as the outcome of a society gone wrong, because real development is the development of the mind and heart. The lives of PLHA end in suffering of the body, mind and spirit because of the limited care and rejection by society. Therefore, a Buddhist monk should provide both physical and spiritual healing for those people (Jessica Bijdendijk, 1996).

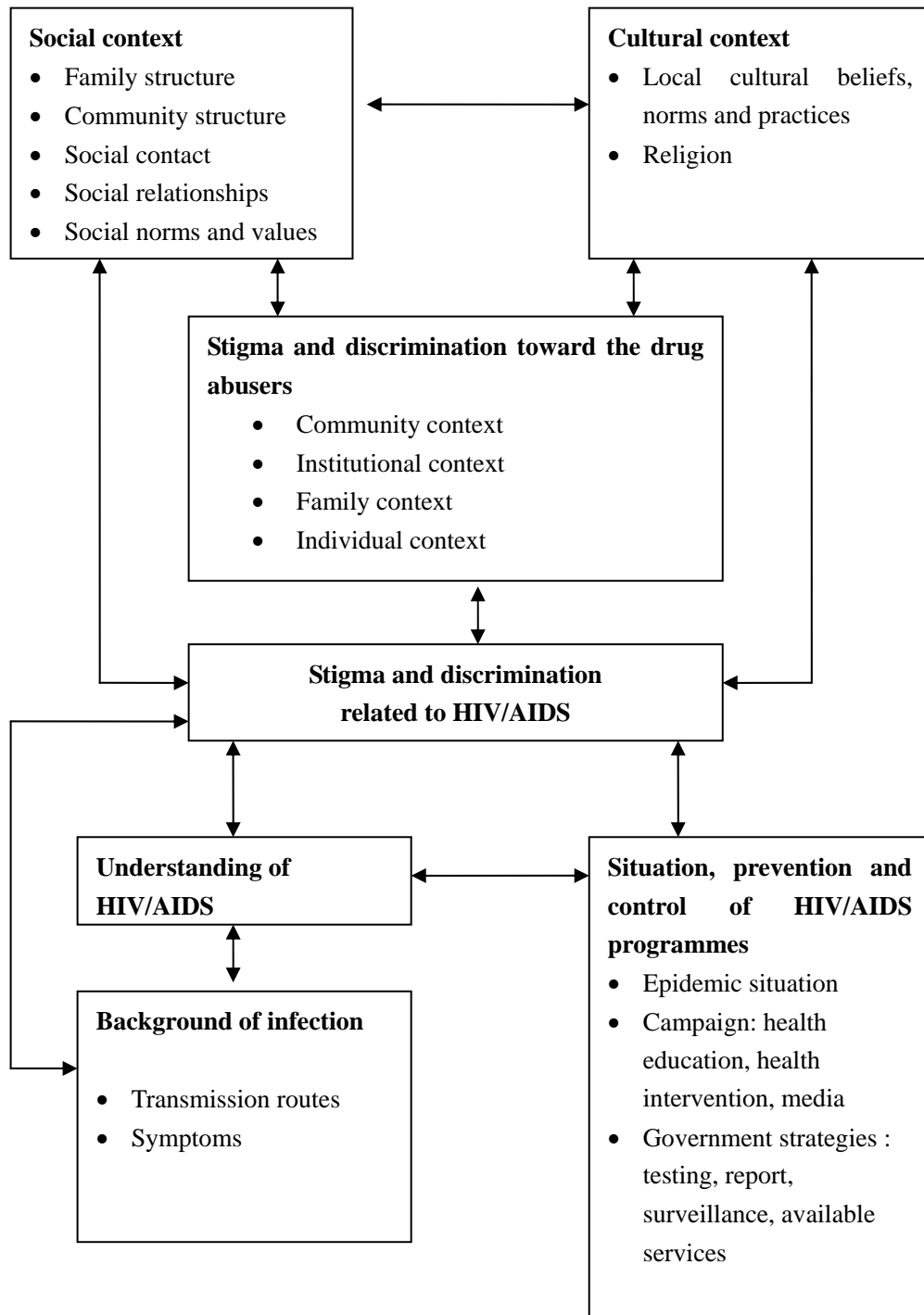
3. Conceptual Framework

The diversity of responses to HIV/AIDS is a complex issue which results from the impact of the epidemic on different communities, and the nature of socio-cultural and economic conditions. It is impossible to fully understand each response in isolation from the social and cultural contexts. Describing and explaining the stigma

and discrimination, a crucial negative response will provide a deeper understanding which may also be helpful for the design of new interventions. However, in order to address this issue, it can not be explored or studied from just one perspective. Multiple viewpoints should be included and contribute to the study. The conceptual framework was developed based on the literature review but completed and modified in terms of the field work.

In this framework, all the elements impact on each other or interact to some degree. A central part of the framework explores the stigma and discrimination surrounding the issue of HIV/AIDS in the Dai community. As the literature review showed the stigma and discrimination in relation to HIV/AIDS can occur anywhere and at anytime and in different forms. So, in this study, the researcher will try to identify and answer whether the stigma and discrimination in relation to HIV/AIDS exist, and why and how they exist in the Dai community.

According to the field work, the stigmas and discrimination related to HIV/AIDS underlie the stigma and discrimination toward drug abusers in the community. They are manifested in the community, social institutional, family and individual contexts. Social and cultural contexts not only shape the stigma and discrimination, but also influence the forms and extent of the stigma and discrimination. Moreover, the understanding of HIV/AIDS and HIV/AIDS campaigns as well as the symptoms impact on or reinforce the stigma and discrimination in relation to HIV/AIDS.



CHAPTER III

THE RESEARCH METHODOLOGY

Dehong prefecture is located in the southeast of Yunnan province. It is around 800 Km from Kunming, the capital of Yunnan. When I proposed to perform this research, I wondered which area would provide the best study site within the Dehong prefecture, and how I could reach a site located in remote and mysterious areas inhabited with many ethnic groups. Fortunately, with the help and advices of my boss, Prof. Kaining Zhang (He has conducted several projects in cooperation with the local government in Dehong.), I decided that Yinjiang County would be an ideal site for my study. Later on, I got in touch with Dr. Duan, the manager of HIV/AIDS prevention and control program in Dehong. Later, we met face to face to discuss my research topic and it's implementation after an 18 hour bus journey from Kunming.

With Dr. Duan's help, I reached Yinjiang County after 3 hours and organized a meeting with Dr. Ming, the director of the health bureau for Yinjiang County to address my research objectives and discuss the details of my study site. After confirming all the details, he sent me to Xincheng Dai community. When I got there, I was surprised by the beautiful landscape, and it was beyond my imagination and expectations. The panorama of Xincheng community looks like a maiden lying on the bank of the Yinjiang River embraced by verdant mountains and flourishing bamboo forests. Several misty valleys accompanied by green undergrowth and blooming flowers extend far into the distance where, a view of the village is clearly visible.

Aunty Feng was the hostess of the family where I stayed. She was warmhearted and I received a great welcome from all the family members with open arms. This is a typical household in this community composed of 6 members: mother, father, son, daughter-in-law, daughter and 1 year old grandson. They can speak mandarin very well so there is no language obstacle between them and me. At first, I was restrained because they perceived me as a guest, an urban girl, a stranger and they did not allow me to do anything except watch TV. I thought I must participate in their lives and on my own initiative showed them my ability to live. Thus, I got up early and helped aunty Feng feed the pig or cook breakfast. When they went out to farm, I did all the housework, such as taking care of the child, cooking, washing, and feeding the domestic animals. At night, I shared my life story with them. I perceived them as my real family members and cared for everyone with a warm heart. After a few days, their hearts were touched and they looked at me with new eyes. Since that time, I have really been accepted by this family so that I can go anywhere they go and practice anything they do. I also had the chance to communicate with other villagers. I greeted everyone with a smile, talked to everyone with respect and helped everyone with my heart. Finally, I was familiar to most villagers. They invited me to have dinner together or attend social activities. They told aunty Feng: “how lucky you are having such a great daughter. We do not know whether we can be as lucky as you in this life.”

While immersed in people’s daily lives, I was anxious in regard to my data collection because of local government worries concerning the reputation of the community; they are very sensitive to the issues related to drug abuse and HIV/AIDS. I did not know who would support me and how I could take the first step. In the first month, I did not carry out any interviews or focus group discussions, nor did I ask any questions related to my topic to the villagers. I just tried my best to get the trust and support of the local people. As a result, aunty Feng suggested I look for Dr. Li, the director of township health center. She was the only person who knew the real

situation of HIV/AIDS epidemic in this community. She was also responsible for the HIV/AIDS prevention and control program there. She always took care of drug abusers and orphans, so she was called the mother of drug abusers and orphans.

After I had visited her family several times, she consented to share the information she knew and gave me a hand. One month later, Dr. Li perceived me as her relative and a good relationship developed between me and her as a result. She not only shared information on the Dai people but also provided data on HIV/AIDS. Thus, I intended to visit the PLHA's families one by one according to my sample selection. Nevertheless, in reality, half of the PLHA had died, some of them were in jail or the Drug Addiction Treatment Center (DATC) and some of them were missing. So, I had to change my strategies. Firstly, I asked Dr. Li to be my linkman. If she saw any PLHA anywhere, she would call me immediately and I would get to there as soon as possible. Secondly, I invited family members whose children, spouses or parents were in the DATC or had died of HIV/AIDS to be respondents instead of PLHA themselves. Actually, I gained further insights into the lives of PLHA through the family member's perspectives and also cross-checked the information that I got from PLHA.

Before visiting each family, I made an appointment and reaffirmed the purpose of my study as well as to guarantee confidentiality for them during and after the study period. In addition, the respondents were told they could refuse to answer any questions they did not like, and they could leave the interview whenever they wanted. Tape recorders and digital cameras were used with the permission of respondents. Normally, I spent 2-4 hours to conduct an interview with each family but I visited some families more than once, if it was necessary and possible. During the interview, I did not only ask questions, but also allowed my interviewees to describe their experiences from their heart. Sometimes, I took Dr. Li as a colleague with me because people trust her very much and I can also confirm the information with her. Day by

day, I gradually found the real answers to my research questions through interviews, discussions, conversations and observations.

The field notes were recorded, arranged and reviewed every day in order to record every detail of the observations and interviews as soon as possible. While reviewing field notes, I also decided what future questions should be added and what should be ignored by me. Before I left, I reviewed my field notes one last time to make sure nothing was omitted.

Three months later, I had enough rich and wonderful information, so I decided to end my data collection. When I left, the villagers held a great send-off party for me and many of them cried. Dr. Li and aunty Feng hugged me tightly and said: “We are going to miss you all the time. If you have time, please come back here. This is your second home.” By the way, a serious flood took place during the period of my data collection, so I had to stop work and take a short break in Kunming.

The following paragraphs are a summary of my research methodology including the research approach and research instruments that the researcher applied to target groups involved as informants.

1. The Research Approach

This study employed qualitative methods to explore the psychosocial, contextual and behavioral topic---stigma and discrimination in relation to HIV/AIDS in the Dai community. Qualitative methods are highly effective in understanding the psychosocial or contextual issues and exploring underlying factors contributing to the issues in a specific community. They enable us to better understand people’s lives and capture values, perceptions, attitudes and the beliefs of people.

I started to immerse myself in the daily life of the Dai people. Living in the community and presenting myself as a community member was the first step to understand the environment of the community and the daily life of people. It also enabled me to create a trustworthy relationship between researcher and villagers. After gaining their trust, informal conversations, in-depth interviews, and focus group discussions were applied to data collection. In addition, during the data collection period, participatory techniques such as transect walks, community mapping and participant observation were also conducted to get an insight into the community layout and confirm the information obtained from interviews and discussions.

2. The Study Site and Population

The study was performed in the Xin cheng Dai community of Yin Jiang County in Yunnan province which has a high rate of HIV infection. The interviews were normally conducted in the houses of PLHA. However, sometimes, I met respondents accidentally, so I deferred to their preference or we chose a comfortable and private place such as field, or a private room in the health centre. For some respondents who were still in the detention centre, I had to interview them inside the centre to avoid rearranging my schedule. For each focus group discussion, I chose one house of the community members which was more convenient for every participant.

Actually, two major groups form my study population. On the one hand, to explore the lives of PLHA, PLHA and their family members are the major target group. At this level, I not only looked at the experiences of being PLHA but also paid attention to the background of each family and the experiences of being a drug abuser. This study examined different contexts and institutions such as the workplace, school, health service center and religious rituals to account for how PLHA or family members live in the community, how they perform or complete their social roles and

how they cope with the stigma and discrimination.

On the other hand, for a better understanding of the lives of PLHA and to confirm the information, other community members were involved in this research, including leaders of community and religion, health professionals, teachers, traditional shaman and general villagers. Detailed information will be provided in the following section.

3. Data Collection Methods

Three months of the research adopted participant observation, in-depth interviews, informal conversations as well as focus group discussions with opportunistic samples of villagers for the data collection. Field notes, tape recordings, and photographs as a data record were used with the permission of informants. Field notes were the main method of keeping records. These contained the contents of observations, conversations, interpretations and inferences.

3.1 Participant Observation

Participant observation was the primary research method in this study. This helped me to better understand the lives of PLHA and be able to describe customs and beliefs of the Dai people. Participating in people's daily lives, participating in interviews or conversations as a learner are the keys for good observations. The observations were conducted not only of the whole community but also of each respondent and ran through the whole process of data collection. A guideline was developed to guide the observations (See Appendix).

Observing the community setting and the daily life of people was the start of collecting basic information. Some special traditions or religious rituals or customs

were also observed by the researcher. And then, observations focused on the lives of PLHA and their families. During the in-depth interviews, focus group discussions and conversations, the reaction, expression and body language of the respondents was also observed. Such observations enriched the data as well as enabling me to get many vivid pictures.

3.2 In-depth Interviews

In-depth interviews were main tool for data collection because they are a good way to explore the lives and experiences of PLHA in community and underlying factors.

Samples selected in this study do not rely on rigid sampling methods. This is not a random sample across society, but it does reflect a broad slice of experiences. Once the initial informant was selected, snowball sampling and sampling typical cases were also used for sample selection. Maximum variation technology and purposive samples were used to overcome the weakness of snowball sampling. Based on Dr. Li's information, I selected informants in terms of sex, education background, marital status, family background, heroin taking history and the time of being infected. For example, two female PLHA were involved. The informant who had the highest school age or who had a long addiction history or whose family had many drug abusers or who was the first person identified as being infected in the community were selected. Finally, 22 families were selected from the Dr. Li's list. 2 cases were introduced by one respondent after interview and 2 cases were interviewed by chance. All the PLHA who were at home were found and interviewed.

In total, I have visited 26 families and 29 respondents from these families have taken part in in-depth interviews including 9 PLHA, 3 wives, 4 children and 13 parents

of PLHA. Although some families have more than one PLHA, my interview focused on one PLHA as an informant in each family so that I could gain details clearly. Except for two women, all the informants were both drug abusers and PLHA. Table 3-1 shows the background of each case.

Table 3-1 Background of Samples

N o.	First time of drug abuse	Years of heroin taking	Confirmed infected	Present status	Marital status	Education	Number of IDUs in family	Respondents
1	1989	15	1993	In DATC	unmarried	Primary school	1	parents
2	1996			Disappeared	divorced	Primary school	2	Orphaned daughter
3	Infected by husband			Died 2004	married	Primary school	1	Orphaned daughter
4	1982	20	1992	Died 2002	unmarried	Primary school	1	father
5	1990	12	1995	Died 2002	married	Junior school	1	Mother and wife
6	1988	15	1995	Died 2003	married	Junior school	1	wife
7	1991	11	1999	At home	unmarried	Junior school	1	self
8	1997	7	1999	At home	unmarried	Junior school	2	Mother and self
9	1989	12	1995	Died 2001	unmarried	Primary school	4	Mother
10	1989	12	1995	Died 2001	married	Junior school	2	Parents
11	1992	10	1999	Died 2002	unmarried	Primary school	3	Father
12	1996	8	2004	At home	divorced	Junior school	2	Self
13	1994	10	1997	At home	married	Technical secondary school	1	Self
14	1985	19	1990 (first case in this community)	In DATC	unmarried	Junior school	4	mother
15	1994	10	2004	At home	married	Primary school	1	Self
16	1990	10	1997	Died 2000	married	Junior school	1	Wife
17	1988	12	1995	Died 2000	unmarried	Junior school	1	Mother
18	1991	13	1997	In jail	unmarried	Junior school	1	Mother

N o.	First time of abusing drug	Years of heroin taken	Identified time of being infected	Present status	Marital status	Education	Number of IDUs in his family	Respondents
19	Infected contact	through	sexual	Died 2001	married	Junior school	1	Orphaned son
20	1991	10	1997	Died 2001	married	Junior school	1	Orphaned son
21	1989	15	1995	At home	married	Junior school	1	Self
22	1990	13	2000	Died 2003	unmarried	Junior school	1	Father
23	1990	5	1993	1995	unmarried	Junior school	1	Father
24	1992	12	1995	At home	unmarried	Junior school	1	Self
25	1977	27	1995	At home	divorced	Primary school	2	Self
26	1994	10	1999	At home	unmarried	Junior school	3	Self

Moreover, to cross-check and get richer information, other key informants and villagers were involved in this study. 8 key informants were intensively interviewed. They were 2 teachers, 2 doctors, 1 community leaders, 1 shaman, and 2 villagers.

All participants were involved voluntarily. After the interviews, every respondent received a gift as a thankyou such as a towel and soap. But for drug abusers, many of them asked me for money directly.

Interview guidelines was developed (See Appendix) before conducting this study, including structural questions, descriptive questions and contrasting questions in terms of PLHA and the different informants. And a pretest of the guidelines was conducted among three respondents. Based on the information collected from the pretest, the guidelines were revised using local terms.

3.3 Informal Conversations

Informal conversations were applied as an accessory to data collection. Before going into the field, two people who were familiar with Yinjiang county and Xincheng village were invited to share information. During the process of the field work, informal conversations were conducted with students and villagers. The purpose of which was to better understand the living conditions of PLHA and orphans as well. After returning from the study site, two professors who are experts on the Dai culture were interviewed by me in order to confirm my findings and inferences. In addition, existing documents were reviewed and collected as another channel to gain documentary evidence.

3.4 Focus Group Discussions

Focus group discussions in this study were adopted for general community members in order to enrich the data and cross-check the information from another perspective. Four focus group discussions were done among 20 participants. They were not drug abusers or PLHA and there were no drug abusers and PLHA in their families. They were selected in terms of sex, age and marital status. Participants had heated discussions on the questions raised, without any of the expected hesitancy or shyness. Discussion notes were made during the discussions and completed immediately after discussions.

The use of multiple methodologies confirms the validity and reliability of the findings. For instance, I asked one respondent whether he had ever shared needles with drug-using friends, to which he replied “never”. Later, I checked this information by asking his drug-using friends. Participant observation can also be a good way to check the validity and reliability of information. Table 3-2 shows a brief summary of

data collection:

Table 3-2 Summary of data collection

Research Questions	Main tools for data collection	Informants
How do PLHA live in the Dai community?	In-depth interviews Participant observation	PLHA and their families
Why do stigma and discrimination exist or not exist in the Dai community?	Participant observation In-depth interviews Informal conversations Focus group discussions	Key informants (health professionals, leaders of the community, teachers, etc.) Possible informants (students, professors, etc.) Community members

4. Data Processing and Analysis

Firstly, the data (field notes and records of interview) were reviewed, coded, edited and analyzed in the field in order to find new emergent information and guide further data collection. After the field work, all the data from tapes, and field notes was transcribed, jointly collected and cross-checked. Integrating and comparing of all cases were carried out carefully. The computer was used to complete and rearrange the manual data analysis. Several local terms related to my topic were collected to help me better understand the information. (See table 3-3)

Table 3-3 Translations of the slang used among local people

Slang term used among community members in Chinese or the Dai language	Translation	Real meaning
Si Hao	No. 4	Heroin
Si Xiao Jie	No. 4 beauty	Heroin
Si Hao Ke	No. 4 person	Drug abuser
Chi	Eat	Snorting and smoking heroin
Da Zhen	Injection	Injecting heroin

Slang term used among community members in Chinese or the Dai language	Translation	Real meaning
Hao Ren	Good person	Non-drug user
A La Xi Ya	Junkies' disease	HIV/AIDS
A La Bing Dong	Junkies' impetigo	HIV/AIDS
Yan Dan Bing	Patient	If this word was used by drug abusers, it means PLHA
Hai Gun	A person who sell their arse	Sex worker

5. Ethic consideration

This study is a sensitive study because it relates to HIV/AIDS which is a challenging and sensitive issue in Chinese society today. Moreover, private history and personal lives were explored. Thus, it is necessary to consider the ethical issues to protect participants and patients' rights and dignities while conducting this study.

- I have explained the purpose and significance of this study to the respondents.
- During the interview, I respected and treated equally every respondent without prejudice and tried not to make respondents suffer from emotional distress.
- The proposed respondents voluntarily made decisions as to whether to participate in this study or answer any particular question. They were allowed to drop out of the study at any time without obligation.
- The respondents had the right to ask questions and interrupt the conversation.
- The tape recorder and digital camera were used with the permission of the respondents
- I took responsibility for the confidentiality of all information. All the participants will be anonymous and personal information such as the social background of respondents, and the background of PLHA were sealed or destroyed after use.

CHAPTER IV

THE BACKGROUND OF THE COMMUNITY AND THE CHARACTERISTICS OF THE DAI PEOPLE

Chapter IV provides background information about the study site and the Dai people. This chapter consists of three parts: the geographic, demographic and economic backgrounds of the community are the first part. The drug abuse situation and the prevalence of HIV/AIDS as well as the HIV/AIDS prevention and control campaigns which make up the second part. The third part is the socio-cultural characteristics of the Dai people.

1. Xincheng: A Small Frontier Community

The study site is the Xincheng Dai community of Yingjiang County in Dehong prefecture. Yingjiang County is located in the southeast of Dehong prefecture with a total area of 4,429 square kilometers. It is 864 Km from Kunming, the capital of Yunnan Province. This county borders Kachin state in Myanmar with 33 routes and 6 roads transferred by cars or trucks. Hence, it is an important trade centre between China and Myanmar.

Towards the end of 2001, Yingjiang county had a total population of 259,496, among which 154,200 were minorities, making up 59.9%. The Dai people are the biggest ethnic group with a population of 95,800 at the end of 2001.

Yingjiang County is a typical agricultural county. Sugarcane and paddy are the main products and financial resources to farmers. The average income per person per year is US\$400. Administratively, there are 7 towns and 12 townships, 99 administrative villages and 996 natural villages. Towards the end of 2001, at the county level there were 5 health facilities and 338 health workers, at the town/township level, there were 18 health facilities and 198 health workers, at the administrative village level, there were 96 health facilities and 172 health workers.

The Xin cheng Dai community is a central and typical Dai community located in the east of Yingjiang County. It is 31 Km away from the county centre. The total population is 2048, and 90% are the Dai people. Planting sugarcane and rice are the major braces for economic development. Some people also run some small businesses in their spare time such as selling food or vegetables in the market. Some take part time jobs such as construction workers. However, the gap between the poor and rich is not serious. The average income of one person is around US\$120 per year.

The Jinpo and the Deang are neighboring ethnic groups as well as the Han people who live in the vicinity of this community. There is a market day every five days in the main street of the community. In the market day, many outsiders including the Jinpo, the Deang and the Han people, and even some Burmese will come and share their products at the market. For transportation, minibuses and tractors are available everyday going to the county centre or neighboring communities. Telephones and mobile phones are major communication tools for the Dai people to contact outsiders.

2. “Si Hao”, HIV/AIDS and Campaigns of Dai People

2.1 “Si Hao” and “Si Hao Ke”

“Si Hao”, a local term that means No. 4 but is used to refer to heroin because different numbers refer to different opiates according to their components and purpose: “Yi Hao”(No. 1) is opium, “Er Hao”(No. 2) is morphine and “San Hao”(No. 3) is bhang. Thus, “Si Hao Ke” (No. 4 person) was the name given to drug abusers in this community.

Although Xincheng Dai community is not very big, there are more than 150 “Si Hao Ke” including 50 deceased people at the end of 2003. The youngest was 19 years and the oldest was 70 years old. All the “Si Hao Ke” are male and most of them have taken drugs for more than 10 years.

The geographical location of this community is one of main reasons for the popularity of “Si Hao” here. Although heroin is prohibited, it is still smuggled across the border on account of the great profit. Thus, it is cheaper and easily available than places inland. Respondents told me that they can find different types of “Si Hao” on the market in terms of quality and price, from US\$0.3 up to US\$3.

To stop trafficking in drugs, the government has organized a series of campaigns cooperating with other departments or communities. Abusing and trafficking drugs is illegal in China so the public security department can arrest drug abusers or dealers with enough evidence. Drug dealers will be judged by law and put in jail. For drug abusers, they will be imprisoned in Drug Addiction Treatment Centers (DATC) for detoxification and rehabilitation for 3 or 6 months. But if they can not stop the habit and visit the DATC several times, they will be put in jail for 3 or 8 years.

Moreover, in this community, there is a special team made up of local governmental officials and villagers to educate people on the harm of heroin. The information and national policies on the prohibition of drug abuse also are diffused through their activities. A one month abstinence campaign is conducted every year. During this period, all drug abusers must stay in one place and guards and parents are allowed to send in food.

2.2 The Fight against HIV/AIDS

“March 20, 1990 was a special day that I remember clearly because on that day, the Yingjiang Center for Disease Control and Prevention (CDCP) identified the first batch of HIV-positive cases from blood tests that they had from several drug abusers in our community and neighboring communities. That was the first time when I heard of HIV/AIDS. Between 1990 and 2000, the government did not pay much attention to this disease, so the rate of infections was increased quickly year after year. Since 2000, when the government started working on this issue in our community, the newly infected population has come down.”(Dr. Li, the director of the Health Center in Xin Cheng community)

To confirm Dr. Li’s description, I have reviewed the existing history of Yingjiang CDCP. Yes, it is true that the first case of HIV/AIDS in Yingjiang County was reported in 1990. According to the report, by the end of 2003, there were 1068 people infected with HIV in Yingjiang, and 84% were farmers. Sharing intravenous equipment among drug abusers is the predominant way of HIV/AIDS transmission. Eighty percent of infections are from sharing needles and the infection rate is increasing year by year ranging from 4.2% in 1992 to 46% in 2003. Transmission through sexual contact and infected mothers is also increasing recently.

In Xincheng community, 64 people have been infected by HIV until now and 35 of them have died. Sixty-two PLHA are male as well as being drug abusers infected by sharing needles, and only two PLHA are female infected through sexual contact. The

oldest is 50 years, and the youngest is 23. Only 38 PLHA have ever gotten married. Fortunately, no children have been infected because their fathers started to use drug after they were born. However, 15 children have lost their parents because of drugs and HIV/AIDS. Most of them are living with their grandparents and some of them have been adopted by relatives or neighbors.

As the staff from Yingjiang CDCP share information, in this community, the Yingjiang CDCP almost every year carries out free HIV tests for drug abusers. Besides this, almost all drug abusers who have been arrested and sent to the DATC are requested to take a blood test. For those whose HIV test is positive, they will be registered and supervised by the Yingjiang CDCP. The staff of the CDCP will inform one or two family members of the infected person and diffuse basic knowledge, such as the transmission routes of HIV/AIDS as well as provide free condoms to spouses.

Few grass-roots doctors participate in the campaigns of HIV/AIDS prevention and control, so they are service providers and programme executants or coordinators in the front line. They not only understand the HIV/AIDS prevalence in the communities where they live, but also provide health services, even creating living conditions for all PLHA and family members. In addition, they report all the information to the CDPC regularly. Dr. Li is the only person at the study site who has been engaged in this program for 10 years.

In 2000, two HIV/AIDS intervention projects came into effect in this community. One is Peer Education on HIV/AIDS supported by the Australian Red Cross and the Yunnan Red Cross. In this project, all the peer educators are PLHA or spouses of drug abusers. The other one is a community-based care program in cooperation with the United Nations Children's Fund and the women's federation of Yunnan province. This project aims to support the tuition and living expenses of orphans.

3. A River People with a River Culture: The Socio-cultural Characteristics of the Dai People

While summarizing some socio-cultural characteristics of the Dai people, I imagined “A river people with a river culture” to describe their typical traits. Most Dai communities have settled down along the river, so the river nurtures every community. By imbibing aspects from other ethnic groups in its long historical development, the Dai culture has formed into a multi-cultural river culture incorporating successive generations of the Dai people as well.

Ethnic groups are defined as small societies within a larger society that displays a unique set of cultural traits. Members share a common cultural tradition or what they believe to be a common cultural tradition and have some degree of consciousness of being different from other groups and consider themselves to have common roots. Martin N. Marger concludes that ethnic groups normally have 5 characteristics—a unique culture, a sense of community, ethnocentrism, ascribed membership, and territoriality, but these characteristics can be displayed to different degrees by different ethnic groups (Martin N. Marger, 1996).

The Dai people are a diligent and kindhearted ethnic group in Yunnan, China. The total population of the Dai people is around 1 million, and 60% of them live in border areas such as Xishuanbanna and Dehong, or live along the Honghe River and the Jinsha River due to water worship. These areas lie a little above sea level, and are part of the subtropics, so the weather is warm and moist.

The Dai culture, with its colorful features, is a neutral force bestowed by the ancestors of the Baiyue and which has absorbed many strong points from other ethnic groups. Therefore, as can be seen from dress, language and customs, special cultural

traits have come into being. Here, based on the research topic, the information just focuses on: the structure of the community, the family structure, social relationships, marriage and sexuality, the perception of illness, death and religion.

3.1 Starting with the “Mang”

Usually, a river is the center of each Dai community and composes several natural villages. A natural village is named a “Mang” or “Zhai Zi” and is a productive unit in the Dai community. A few families make each natural village which has its own common fields and irrigation system. Each natural village has one leader whom was elected by the villagers and regulates all the members and organizes social activities of the village, including the distribution of fields, absorbing new members, arranging religious or traditional rituals and meetings.

An agreement was made by all villagers and supervised by the leader. It regulates the village and people’s behavior which will be effectively restricted. In addition, there are many unwritten moral norms enlightening people’s behavior. For example, many villagers shate: “being people here, we must be faithful, honest and friendly which are basic norms for everyone in the Dai community. Shifty, idle youths are looked down on by others...Men should abstain from 4 evildeeds: cheating, stealing, dallying with married women and rape. Women should not be sloppily dressed, loquacious or idle.”

The Chinese government attempted to combine several natural villages to be one administrative village called “Xing Zheng Cun” which is easier to manage by the government. Therefore, in each administrative village, a government office was set up to manage attributive natural villages. Normally, a health center, school, temple and market are also available at the administrative village level. The study site is one

“Xing Zheng Cun” composed of 4 natural villages with 1 health center, 1 primary school, 1 market and 2 temples forming a rounded community.

The Dai people are very united. They regard the whole community as a big family so peace in the community should be maintained. If somebody’s behavior breaks the rules, they would be punished accordingly. For instance, stealing is taboo within the community. The thief should be punished with a fine or by forfeiting.

3.2 Our House Along The Orientation of Sunrise

By visiting several households, I understand the construction of the Dai house as well as its unique meaning. Commonly, each house has 5 rooms: a living room, 2 bedrooms, a kitchen and granary. The living room and bedrooms must face the orientation of sunrise because people can easily identify the time by looking at the sunrise and sunset. East, therefore, is regarded as a superior orientation. Unmarried children live with their parents. Once a son gets married, only one son and daughter-in-law can live with the parents and the others should live apart. For daughters, they normally live with the husband except for those families which have no sons.

3.3 Our Duties, Our Roles

When I was in field, I observed that everyone contributes to the community with his/her given duties and social roles. As an ethnic group, they have their own rules or system to divide social groups among community members. I wondered how this system works, so a visiting professor shared his invaluable experiences with me. Generally speaking, in order to fulfill different social duties and complete common jobs, the Dai people can be divided into 5 social groups based on sex and age. 1) The older male group: this group has higher social status and is responsible for distributing

fields and duties to community members and organizing the religious or traditional rituals; 2) The young male group: this group is organized to deal with public jobs such as solving the mutual problems of different villages. If a war takes place, they should protect their own village; 3) The older female group: this group just performs housework and handiwork but they are respected by the other groups. They can also organize traditional rituals; 4) The young female group: this group undertakes most of the housework and fieldwork; 5) The children's group: they just help adults with what work they can. In short, the Dai people have great respect for those who are older.

Moreover, by observing and interviewing, I realized that gender relationships are different in the Dai community to others. On the one hand, women undertake most of the housework and fieldwork so they have higher a status in the family and are more independent. They are decision makers and property sharers. On the other hand, the heavy work load can also be regarded as a representation of gender inequality. They are busy with housework and fieldwork from morning till night. “Yuan Dang Baiyi De Ma, Bu Dang Baiyi De Mama” (I prefer being a horse of the Dai people rather than being a mother of the Dai people) is a common saying, meaning that married women in the Dai community are more exhausted than anyone even the horses on account of their heavy work load. Moreover, we can also see the inferior position of women in other aspects. For example, one day, when we were going to have dinner, I asked aunty Feng to take a seat in a superior position (eastern position). She was embarrassed and told me: “Oh, I cannot sit there, being a Dai woman, we are not allowed to sit in that position. It is just for men, otherwise I will be ashamed.”

In addition, I also noticed that a “relative” is an important and broad concept for the Dai people. People are related by kinship, a common origin, or marriage. Thus, it seems the countless ties of relatives link the whole community together. As relatives, they help and contact each other. For example, wedding parties or funeral parties or

similar social gatherings need extra hands to hold the ceremony, so sharing labor among the relatives has become a traditional convention and all the relatives or friends must attend the ceremony. In the busy farming season, mutual aid organizations are important systems to maintain the development of agriculture and the domestic economy. People are used to exchanging labor among relatives.

The interviewed professor also mentioned that on account of the common ecological environment, the same socioeconomic background and the countless ties of relatives, coherence has become a significant cognitive characteristic of the Dai people. It not only affects people's thoughts but also affects people's behavior.

3.4 Early Love, Early Marriage and Early Childbirth

Early love, early marriage, and early childbirth are perceived as major sexual and reproductive characterizes of the Dai people. From 13-14 years of age, girls and boys are able to enter a special association developed for the young generation to look for a partner. However, premarital sex and extramarital sex are prohibited and offenders will be punished by the regulations of the village, especially for those who perpetrate these crimes inside of the village. "Xi zhaizi" is a common punishment: by making a sacrifice to the community of money or goods, offenders must offer all community members an apology for not following the regulations and breaking the peace.

The Dai people believe in monogamous marriage and they can feel free to choose their spouse. After getting married, the wife follows husband to live with his parents but if the wife's parents request it, the husband can also stay in the wife's house. The couples are allowed to set up their own household when the following requirements are fulfilled: the younger brothers or sisters are able to undertake farm work and housework; the parents are able to provide partial financial support to the newlyweds;

even if the above two conditions are met, the new couple must live with the parents for 1 year. During this year, newlyweds should prepare to construct a new house, such as saving money from taking extra work, and making provision for timber.

The Dai people prefer to give birth as soon as possible after getting married because they believe that women are free after the delivery. They also prefer to have one or two children whether are female or male. This ideology is unlike the majority of people in Chinese society which may result from less influence on the consciousness of carrying on the ancestral line. Both fathers and mothers love children but the mother is the only one who should take care of the children in most Dai families.

3.5 Between Normal and Bewitched

In this community, on the one hand, the Dai people think being taken ill is normal for everyone. Thus, seeing doctors and taking care of sick people are also perceived as normal actions. The modern health care system is supplied by a three-tier network, namely, the county hospital, the township health center and the village clinic but only the health center and the village clinic are located in the community. On the other hand, there is an integrated medical system in the Dai community which influenced strongly by Buddhism. People absorb the ideologies of “4 Ta” and “5 Yun” from Buddhist scriptures to diagnose illness while taking traditional medications. “4 Ta” means four natural elements: wind, fire, water and soil which are used to explain the growth of human beings and human physiology. “5 Yun” refers to human appearance, feelings, consciousness, tissues, organs and senses, which are used to reflect physical and mental well-being. In addition, the Dai people also believe in ghosts. They believe those people who can not recover from prolonged illness or who get acute diseases

must be bewitched, so they should visit and ask the shaman to apologize for their offence.

According to my observations, nowadays, choosing treatment in hospitals as the first choice is much more popular than before. This can be attributed to the development and interposition of modern medicine. However, this does not mean that people have given up demonology. Some people still visit the shaman to expel evil spirits or malign influences, while taking modern medical treatment or traditional herbs, especially for chronic or acute illnesses.

3.6 Death: Termination and Beginning

The Dai people consider death to be the final of tribulation of people in this world. It's a chance to earn merit for the next life and give each his comeuppance in evaluation of the last life. If you were generous before your death, you would not only be able to go to heaven but also be free from tribulation in the next life. Therefore, the funeral ceremony is an important social activity. From the moment of reporting the death, all the relatives and friends, even all the community members of the deceased, will be involved in the funeral ceremony. By donating money, goods and labor, the funeral ceremony will be carried out.

Incidentally, I had two opportunities to attend funeral ceremonies when I was at the study site. The process and customs of the funeral are complicated. Condolence calls and the practice of keeping the coffin in a temporary shelter before burial are the first stages. At this time, the corpse is washed and wrapped in calico. Family members will sing special songs to show their sadness and monks will chant to show the way to heaven for the deceased.

The next stage is the funeral procession and celebration for the soul of the dead. Choosing the tomb and burial are the main activities at this stage. Only compeers or juniors can carry the coffin and perform the burial in the ancestor's grave area. During the funeral ceremony, paper made to resemble money, houses or people is burned as an offering to the dead.

However, in this community, there are two kinds of death. One is normal death and the other is ominous death. The deaths of elders (upwards of 60 years old) or sick people are normal deaths, but for those who are under 60-years-old and who die from contingency or acute disease are considered ominous deaths. For ominous deaths, the body can not be buried in the ancestral tomb area. A special grave is normally arranged for ominous deaths.

3.7 Let's Do the "Bai"

As the years passed, demonological ideology handed down by the ancestors of the Dai people has developed into primordial religion with multifarious parochial traits. The evolution of this primordial religion has even contributed to the development of Dai society and culture. In the 6—8th century, Hinayana Buddhism was introduced gradually into the Dai community from India. Hinayana Buddhism, which has combined traits of a primordial religion in the course of its diffusion, was invigorated in the Dai community. Moreover, it was advocated and supported, so it has made great progress and strongly influences all aspects of the lives of the Dai people.

Hinayana Buddhism encourages people to be lenient as Buddhists and restricts individual behavior according to the religious doctrine, such as the prohibition for killing, smoking, alcohol abuse and illicit sexual relations. As can be seen from such doctrines, the integration of social ethics and religion is a significant part of the local

unwritten regulations. Furthermore, comeuppance is also an important cognitive credo. Whether you can go to heaven after death, or whether you have a pleasurable or satisfactory time in the next life, depends on the merits and virtues which you earn in this life. Therefore, being kind and warmhearted to others and doing the “Bai” (“Bai” is a Dai language term, meaning devotional obligation.) for Buddha enables you to accumulate merits and virtues. The purposes of doing the “Bai” are as follows: people will go to heaven after death, the offspring will be healthy and wealthy, fathers will live well with enough food and shelter in heaven, people will be free from calamity, people will get the respect and acceptance from others and the community will be free from plague and warfare.

Religious activities and festivals are celebrated all year round so doing the “Bai” can be carried out frequently. In addition, while celebrating Buddhist activities, primordial religious activities are conducted as well, such as memorial ceremonies for numen of the community or family. Normally, Buddhism activities are held in “zhuang fang” (Buddhist temples) and elders and married women are main participants. Primordial religious activities are carried out in “xiaomiao” (traditional altars) and only men are allowed to enter.

CHAPTER V

THE LIVES OF “SI HAO KE”

Before interviewing “Si Hao Ke” (Drug abusers), I had heard local people describe them several times. Many derogatory terms such as “disgusting”, “dirty” and “sickly” seem proper adjectives for “Si Hao Ke”.

When I met Mr. 71 the first time, he was in a street holding a ropey umbrella. I could not believe my eyes because he was so skinny and dirty but I had to believe what people are used to describing. He gawked without any expression and looked like a ghost. However, from our conversation, I realized he was smart and sane. We found a private room in the health center and he shared the following story with me.

Mr. 7 is 31 years old, living with his parents. His elder brother and two sisters are married in other communities but he is unmarriable because no one wants to marry a “Si Hao Ke”. He has used “Si Hao” (Heroin) for 13 years since 1991. “Losing control of my willpower under friends’ temptation” is the reason that he gave for becoming a “Si Hao Ke”. Since that time, he has had to struggle with money and drugs everyday. Sometimes, he asks for money from his parents; sometimes, he works as a farmhand; sometimes, he has to steal from family or neighbours’. Being a “Si Hao Ke”, he is isolated from “Hao Ren”(Non-drug abusers) and only drug friends are willing to associate with him because of the same identity, the same experiences and the same demands. Although he regrets using “Si Hao”, he is not able to get rid of the habit; although his parents never rejected him, he is sorry for his family members; he is hopeless, and pins his hope on the next life.

¹ I use number instead of real name in the thesis

In 1999, staff from Yingjiang Center for Disease Control and Prevention (CDCP) asked him for a blood test, and then He was identified as HIV-positive. However, he was not surprised by his infection because he believes it is a certain fate for “Si Hao Ke”. He does not care about his health status, even HIV, because any disease will not make his life better or worse than it is now. People still treat him as they used to. The identity of ‘Si Hao Ke’ makes a clear distinction between “Hao Ren” and “Si Hao Ke”. Hence, he is not afraid to disclose his HIV status to his family members, even the community.

Before being infected by HIV, he had heard information about HIV/AIDS and knew sharing needles may cause the diseases transmission but dealing with the “Si Hao” craving is much more important than anything else. In addition, because of his hopelessness, he does not pay attention to his health, even giving up seeking medical attention. After being infected, he has avoided spreading the virus to others because he can not afford further misdoings by himself.

The next morning, after meeting Mr.7, I saw Mr.8 squatting in the street. When I asked him for permission to interview, he was glad to introduce his mother so I followed him to his house and interviewed both him and his mother.

Mr.8 was born in 1974. He has two brothers. One is married living apart from the family. The other was a drug abuser and died from suicide many years ago. His father has also died of disease many years ago. Now, only he and his mother (62-year-old) are living together. His house is timeworn and dark. The only furniture---a sofa is worm-eaten. I could feel the springs inside the sofa, when I sat down. I guessed his family was very poor. After the interview, I understood how difficult their lives were!

In the past, his parents were workers in a small factory for the local government. Because they had a regular income their family’s field were seized and contributed to farmer’s families. Thus, after the small factory closed down, his family lost their resources. Now, his mother is sweeping public streets everyday for the government but the reward (\$ 12 per month) is not enough. In addition, due to the long-term drug abuse of her two sons, the living conditions are getting worse and worse.

Mr. 8 was a worker in a power plant after graduating from junior high school. Essentially, his salary was enough for him and his family but he lost his job because of heroin taking. He has discerned how his brother became a “Si Hao

Ke” and what harm resulted from drug abuse. However, he told me that he chose the same road as his drug-taking brother because of overrating his ability under peer pressure.

After being a “Si Hao Ke”, he not only lost his job, he also lost friendships, love, and a “normal” life. He has a lack of communication and understanding from “normal” people including his mother and brother, and he is offish with everything. In 1999, he was diagnosed HIV-positive, but this status is perceived as the disengagement of an abnormal life by him and his mother. He has disclosed his HIV status to his mother and peers. He hopes they will be aware of the infection and protect themselves.

When I did my interview, his mother could not help weeping and blaming Mr.8. She said: “I am so heart-struck. Tow sons ruined their lives by taking “Si Hao”. If I had enough money, I would send him to the Drug Addiction Treatment Center (DATC) but now, I just hope he can be released by death and he can have a better life in the next life...After his brother died, I tried my best to hold a funeral ceremony for him but I buried him far from our ancestral grave in case he disturbs the peace of our family...”

There are 62 male drug abusers with similar experiences to Mr. 7 and Mr. 8. Many of them have died of AIDS. To understand their lives, we must look at the lives of being a drug abuser first, so this chapter describes the real situation, which leads us to understand why so many people are involved with drug abuse, how they share their lives with the community and family members and how they perceive their identities.

1. Heroin Abuse

1.1 The Initiation of Being a “Si Hao Ke”

I wondered why there are so many people involved in drug abuse in this remote and underdeveloped community. After the interviews, I realized that using “Si Hao” is a complicated process. There are multiple factors including social and individual factors that push people to follow the track of using “Si Hao”. At least, compared with

inland, the location of the community contributes to the accessibility and affordability of heroin because it is easier to get heroin. Based on the data, I found that peers always introduce or guide drug use but there are four valuable points explained by “Si Hao Ke” that give more information on the initiation to use “Si Hao”.

1.1.1 Following the Majority Without Awareness of Heroin

Mr.26 was my last informant I met. He has been addicted to heroin for 10 years. Two elder drug-taking brothers have died from an overdose and suicide. His father and mother have also died of alcoholism and cancer. One of his drug-taking brothers was the first person to use “Si Hao” in this community. He told me: “at the beginning of 1990s, ‘Si Hao’ was very popular here. It was a fashionable plaything like Kala Ok. I saw many senior youths using it so I thought I must follow them. I asked my brother to give me some.” (Mr. 26, a 26-year-old, addicted for 10 years)

I met Mr. 24 by chance. He was just released from DATC. Actually, he has been there many times during the last 12 years. When I asked how he was involved in drug use, he said: “Many of my friends used ‘Si Hao’ and they were always getting together to share it. I was curious. I thought it must be fun so I took part in their group.”(Mr. 24, a 30-year-old, addicted for 12 years)

It is true that heroin is in common recognition among youths has and been popular in the community for some time. This information was also confirmed by several key informants. Maybe 15 years ago, heroin was just invading the community. There were not many people who understood the harm of heroin, so a lack of awareness to heroin and curiosity motivated some teenagers to follow the majority. Thus, the previous 15 years were the most serious period of heroin taking in the community. Now, most drug abusers are grown-up ageing from 24 to 35 years old.

1.1.2 Underrating the Effects of Heroin, Overrating Individual Contenance

However, some respondents mentioned that they had heard of the harm of heroin before taking it but they still became a “Si Hao Ke”. Here, I would like to start by quoting two sections of conversation between me and two respondents.

Mr.8 has been addicted to heroin for 7 years. Following is our conversation where he tells me how he became a “Si Hao Ke”:

Researcher: “When did you start to use ‘Si Hao’?”

Respondent: “When I was 25 years old.”

RC: “How did you start to use it?”

RD: “My friends gave it to me.”

RC: “How did they do this?”

RD: “You know, we were always getting together for fun in our spare time. One day, one of our friends brought some heroin and persuaded us to try it.”

RC: “Did you know heroin was dangerous and you would become addicted at that time?”

RD: “I had heard but at the beginning of use, I did not rely on it. I could control my use, so I thought it was not as terrible as I had heard. At first, it made me excited and feel wonderful. When I could not get off the habit, it was too late.”

Mr. 12, a 35-year-old, has been a soldier in the national army. After retiring from the army, he had a job and a wife but he lost everything because of drug use. Now, he is living with his mother. His two elder brothers were “Si Hao Ke” too and died of AIDS.

RC: “I heard that you were a soldier before, how did you become involved in using ‘Si Hao’?”

RD: “After I retired from the army, I took a job in a power plant. One of my colleagues convinced me to try it. He was already a ‘Si Hao Ke’. Actually, I had heard the harm of heroin before, but my colleague told me it will make me float upwards so I followed suit. Yes, at first it was amazing and I was able to control my use. It was not very expensive compared to my salary so I kept taking. Later on, I had no idea that I had adapted to the presence of ‘Si Hao’ and suffered when use was reduced or stopped.”

As their state, at the beginning of heroin use, they were able to control themselves so they underrated the effects of the drug. Moreover, heroin is cheaper here, so most people can afford it at the start of use. Therefore, the intensive amazing feelings of taking heroin keep them trying more even though they have heard of the harm of taking heroin. When they are addicted, it is hard to abstain because of the intolerance of the withdrawal symptoms.

When I interviewed one of the non-drug users, he told me that many of his friends used “Si Hao” and some of them have died. I was very curious why he wasn’t involved in drug abuse like his friends. He seemed to be proud of himself and said: “many of my peers were addicted to ‘Si Hao’. They tried to persuade me to take it several times. Fortunately, due to my unalterable willpower, I never tried it.”

1.1.3 Drug Friends’ Self-concern

As a long-term requisite, heroin was sold by drug abusers using it in order to fulfill their economic demands. Thus, friends’ selfishness drives the senior drug abusers to entice more new comers. This point has been mentioned by a few respondents:

Mr. 15, 35 years old, is an only child in his family. His parents place all hopes and dependence on him but he has been addicted to heroin for more than 10 years. “I knew ‘Si Hao’ is terrible but one of my friends kept persuading me to take it. My friend told me that ‘Si Hao’ was more slap-up than meat, I should try it otherwise I would regret it. Finally, I became addicted to ‘Si Hao’. After that, I had to buy it from him or we shared it together.” (Mr.15, a 34-year-old, addicted for 10 years)

1.1.4 A Victim of Traditional Therapy

As a result of the impact of traditional therapy on the Jinpo community, people use opium to cure chronic diseases there. For chronic patients, they become addicted to opium gradually. Since heroin was available, these people used heroin instead of opium because of the cheaper price and easy access.

Mr. 13's story is a typical example. He is the younger brother of my hostess. My hostess told me that Mr. 13 had high prospects because he was the only one who got a high education level in their family. Unfortunately, he became addicted to heroin through a special reason. “I was a teacher in a primary school 10 years ago. I got chronic gastritis so I often had stomachaches. My uncle got some opium from the Jinpo people and I heard it can treat any disease. Consequently, I started to smoke opium. Although, my stomachache was effectively relieved, I could not stop the habit. In recent years, it is difficult to find opium and the price is quite expensive so I use ‘Si Hao’ instead.”

1.2 There are No Female Drug Abusers

The fact that there were no female drug abusers in this community stimulated my curiosity. According to the answers of many respondents or participants from focus group discussions, I think the gender role of women might explain why there are no female ‘Si Hao Ke’. I conducted two focus group discussions with female participants. When I asked them why there were no female drug abusers in the community, they explained:

“We have a lot of work to do everyday. In the day time, we do field work. After the field work, we must quickly return and conduct housework until the night. We do not have time to get together with friends frequently so ‘Si Hao’ can not be shared among us.” (One participant from a focus group discussion)

“ ‘Si Hao Ke’ are already looked down upon. If a woman becomes a ‘Si Hao Ke’, she would be further looked down on by people because she can not look after her family well.” (One participant from a focus group discussion)

Dr. Li, as a woman in the Dai community, also confirmed: “Why are there no female ‘Si Hao Ke’ in our community? I think it may be because women are so busy. And being Dai women, especially married women, you must be concerned with your family all the time. You must take care of your husband, children and parents-in-law. Besides undertaking heavy work, you must save money for your family so we never use money to buy any stuff which is useless to the family.” (Key informant, doctor, the director of a health center)

As can be seen from the aforementioned statements, the roles and duties of women are different from men and reduce the opportunities to get drugs and even remove the motivation for taking heroin.

1.3 From “Chi Si Hao” to “Da Zhen”

“Chi” means eat but it is used as slang among drug abusers to indicate snorting and smoking. Actually, “Da Zhen” is a common word used in a hospital, meaning injection, but the meaning has been changed to injecting heroin since it is used among drug abusers.

I have noticed that all the ‘Si Hao Ke’ did not inject heroin at the very start. Heroin abuse is a process from snorting or smoking to injecting which is associated with serious health hazards, including fatal overdoses, collapsed veins, and HIV/AIDS or hepatitis.

Theoretically speaking, feeling a surge of euphoria ("rush") accompanied by a warm flush of the skin, a dry mouth, and heavy extremities appear soon after an injection of heroin. Such intense feeling seem more effective than snorting or smoking heroin.

“At the start of using ‘Si Hao’, I just ‘Chi’. One day, one of my friends suggested that if I ‘Da zhen’, I will be in heaven. Since I accepted this suggestion, I have not been able to refuse it any more.” (Mr.26, a 26-year-old, addicted for 10 years)

“ ‘Da zhen’ is very good because it is able to relieve my craving and suffering with a prompt high.” (Mr.24, a 30-year-old, addicted for 12 years)

Most interviewees have mentioned these reasons. Once they taste the impact of injecting heroin, they can not stop anymore. However, besides this reason, many drug abusers mention another two reasons for injecting heroin.

“You know, if we chose ‘Da Zhen’, we could use less heroin to achieve the same intensity of effect as ‘Chi’ so ‘Da Zhen’ is much cheaper than ‘Chi’.”(Mr. 12, a 35-year-old, addicted for 8 years)

Mr. 25 is the oldest “Si Hao Ke” among my informants. He has a 27 year history of drug use. Apart from the above mentioned reasons, he revealed another reason: “Sometimes, when we work in the field, the wind is too strong so we could not ‘Chi Si Hao’. ‘Da Zhen’ is a good way to solve this problem.”(Mr. 25, a 51-year-old, addicted for 27 years)

Consequently, injecting ‘Si Hao’ is done either by drug users longing for the intensity of the effect or in an environment lacking the necessary conditions for snorting and smoking.

1.4 Sharing Needles

Although injecting heroin is considered a more hazardous behavior, the heart of this behavior relies on drug users choosing whether and with whom to share injecting equipment. Both in the village health clinic and the community health center, syringes are available for people who need them and the price is only around 0.2 dollars. However, many IDUs still share their syringes with drug friends. Half of the

respondents reported that they did not know sharing needles may transmit the disease until they were infected, but many drug abusers who know the harm of sharing injecting equipment still take this risky behavior. By looking at the following answers, we may understand what they are concerned with.

“When we are in the field or some place where we used to get together, we do not carry our equipment all the time. If a great deal of pain occurs, dealing with the ‘Si Hao’ craving is much more important than anything else.” (Mr. 7, a 31-year-old, addicted for 13 years)

“At the time when we are dying to use heroin, nobody cares about the injecting equipment anymore. We can use any water to liquefy the ‘Si Hao’ such as rainwater, sewer water and waste water to say nothing of sharing needles.” (Mr.8, a 32-year-old, addicted for 7 years)

“You can not understand such feelings as the ‘Si Hao’ crave, we must use it as soon as possible. I do not care about anything except ‘Si Hao’ at that time even though I know sharing needles is unsafe.”(Mr.12, a 35-year-old, addicted for 8 years)

By this token, the accessibility of injecting equipment and dealing with the heroin crave or withdrawal symptoms are inducements to sharing needles, besides a lack of information on the health hazards. Furthermore, compared to the negative effects caused by risky behavior, release from withdrawal is the priority for drug abusers.

2. Voices from “Si Hao Ke”

2.1 There is No Future

The perceptions of drug abusers toward heroin taking behavior are very interesting. On the one hand, most of them regret heroin use but on the other hand, they are desperate after several failures with treatment.

"I hate myself. If I never touched 'Si Hao', my life could be what I dreamed...I really regret taking it but regret is useless. I could not get rid of it; I could not live without it anymore. Since this situation is the truth, I have given in to 'Si Hao'. I never dream of the future and cope with everyday as a whole." (Mr. 7, a 31-year-old, addicted for 13 years)

"We, the 'Si Hao Ke' are often humorous. Sometimes, I embarrass myself. I make up my mind that I should get rid of it but as soon as the time (heroin crave) comes, I don't care about anything in my life, I don't care if anybody is around me. I am tired of such experiences." (Mr.8, a 32-year-old, addicted for 7 years)

Actually, it is difficult struggle for them with heroin. They hate the drug but depend on it. They want to reject it but can not overcome the withdrawal effects. They are sorry for their lovers but cold to anything and anybody when they crave heroin. Regret, failure and desperation are a vicious circle that exhausts their lives. Moreover, many external factors reinforce their hopelessness. For example, they worry about the next drug use over and over again; they are suffering from malnutrition, and short-term or long-term effects caused by drug abuse; they are confronted with isolation; they are dealing with tipsters and drug dealers.

"I am so tired with my life. I can not go wherever I want to go without worry; I can not do whatever I want to do without control. My life can not be normal like 'Hao Ren' (non-drug abusers). I have to deal with money and drugs everyday. I have to face hunger and sickness. I have to get away from policeman. All these things make me so tired. If time could be reversed, I would never touch 'Si Hao'."(Mr. 25, a 51-year-old, addicted for 27 years)

2.2 Heroin as an Antidote

Above we mentioned that the psychological responses not only inflict mental suffering on drug abusers but also may arouse behavioral responses in them to cope with regret and desperation. Using drugs is a common coping strategy that has been pointed out by several respondents.

“I can not get rid of ‘Si Hao’ and I have no choice so I would rather take ‘Si Hao’ under the present circumstances until I die. When I use it, nothing is in my mind. If I have to die from ‘Si Hao’ one day, I deserve it. It is also the end of everything.” (Mr.8, a 32-year-old, addicted for 7 years)

“‘Si Hao’, at least, can make me forget everything for a while since there is no better choice.” (Mr.12, a 35-year-old, addicted for 8 years)

Heroin as anodyne was used for the treatment of suffering. Although this treatment is short-lived, it may be a good excuse for drug abusers since they were in control of the drug.

2.3 Praying for the Next Life

“I look back with regret on the pain I have caused my family. I am sorry for my parents who gave me life. Sometimes, I went to the “Xiao Miao” (traditional altar) alone to pray for my parents, and also for myself...I hope that I can make up for all these things in the next life.” (Mr.7, a 31-year-old, addicted for 13 years)

Pinning their hopes on the next life is another way to comfort themselves which has been practiced by two respondents: Mr.25 and Mr.7.

“I envy those whose families have no ‘Si Hao Ke’. I have had a wonderful family too: a wife, daughter and 2 sons but I lost all of them because of drug use. (His wife abandoned the family. His son and daughter have been sent to his sister’s family because he has no ability to raise children.) I really regret this but I can not change it, so I just pray that I can be forgiven and be free, and happy in the next life.” (Mr. 25, a 51-year-old, addicted for 27 years)

In addition, family members also pray for them and hope that they can get away from drugs in the next life since disappointing by them.

2.4 End the Life, End the Pain

Many studies indicated that suicide often occurs among drug abusers. In my study, two informants chose this way to leave the suffering, and pressure and get away from the control of heroin.

Mr. 17 had used “Si Hao” for 13 years and he was infected by HIV in 1995 but he died from suicide in 2000. His mother said: “He could not get rid of ‘Si Hao’ even when he knew he had made a mistake taking ‘Si Hao’. One day, he asked me for money again. I did not have any and I blamed him. Later, when I went out, he drank pesticide and committed suicide.” (Respondent, the mother of Mr. 17)

One brother of Mr. 8 was a drug abuser too. He died from suicide. I explored his story from his mother. “In my family, there were two ‘Si Hao Ke’. It was a catastrophe for the family.....The second son regretted his behavior. One day, he asked me to forgive him. If he could have a next life, he would like to be my son once more and make up for all the faults he and his brother made. The next day, he hanged himself.” (Respondent, the mother of Mr. 8)

Although I could not explore the underlying reasons or motivation for suicide, I could still infer that ending life was the only solution for all the problems and suffering caused by heroin and was the strategy to overcome the hopelessness and escape from the reality. In addition, many respondents stated that drug abusers are not afraid of death. Instead, they think that death is the expected end for drug abuse. If death could make up for what they have done, they can realize their dreams in the next life, so dying sooner or later does not make any sense. Furthermore, it is worth noticing that they are brave with death but they are not able to refrain from drug use.

2.5 Less Consideration for Health

Lastly, I want to highlight the consideration of health as a subtitle, it may result from the hopelessness of drug abuse and be related to health seeking behavior among “Si Hao Ke”.

“I do not want to check my health and treat my disease. It doesn’t make any sense. My family has already become poor because of me. Spending more money on my health is worthless. I do not care when I will die. It would be extrication for my family.” (Mr. 7, a 31-year-old, addicted for 13 years)

“I do not want to spend too much energy and money on my health. My life is valueless so there is no need to pay more attention to it. If I have a problem with my health, I have to bear it as best as I can.” (Mr.24, a 30-year-old, addicted for 12 years)

According to the statements of the respondents, they do not pay attention to their health and give up seeking health services. Interestingly, in reality, they still seek help from the health center when they have a problem but they can not afford any medical costs. Dr. Li also told me: “If they get a problem with their health, they always come and ask for medication. They do not have any money, so I undertake the cost from my own pocket.”

3. “Si Hao ”: Change the Life, Change the Family

3.1 Collapse of Family

3.1.1 Poverty

Although this community is not in a wealthy region, the average income suffices the basic living needs and requirements of the people. Comparatively, most families I

visited are getting poorer and poorer on account of long-term heavy drug spending. Especially those families which have more than one drug abuser or where the grandparents and children are left and they are utterly penniless. For example, one family I visited only has three bed boards without mattresses. The grandmother raises her two granddaughters by mending umbrellas. Drug abuse gets families into poverty and poverty confronts the family with a lot of risks which affect their well being in the dire ways: poor living conditions, hunger, illness, and malnutrition. In addition to these risks, infants and small children as well as the elderly are incapable of taking care of themselves in terms of crop failure, and also lose the opportunity of being educated.

3.1.2 The Broken Hearts of Parents

“I raised 6 sons. When they were young, I thought I would be lucky because I could rely on them one day after they grow up. Unbelievably, only the youngest is living with me now. 2 of the 6 sons have died of HIV/AIDS, and 2 of them are in jail and one son committed suicide because he could not stand the suffering brought by his brothers. Now, I feel nothing in my heart, my mind and my soul.....” (Respondent, the mother of Mr. 14)

“I was the former director of this community. I made a great effort to ban heroin during my career. Unfortunately, two of my sons were ‘Si Hao Ke’ too. In fact, they were good boys. They were kind and docile but ‘Si Hao’ made them demonic. In their hearts, there was no family, no parents and no brother except ‘Si Hao’. They could do anything, even kill their father for ‘Si Hao’. I am already brokenhearted.” (Respondent, the father of Mr. 23)

“I have tried my best to help him. I sent him to DATC several times myself. I just hoped that he could get off the ‘Si Hao’ one day as he promised. Finally, my depression turned to despair, when he relapsed time after time...In the last hours before his death, I said to him: ‘your mother is brokenhearted by this life as if a drop in the abysm. I gave you life, brought you up, helped you to get a wife but now, you are just leaving me with your two daughters...’ He did not answer with any words except tears.....You know, my fourth son will come back from DATC next month, I am so afraid the tragedy will happen again.” (Respondent, the mother of Mr.9)

When these parents shared their stories with me, they could not help weeping. I was depressed because I did not know how to comfort them, how to comfort parents whose hearts have been broken by their sons. None of the 13 parents I interviewed were not disappointed in their sons not only because of drug abuse destroying the whole family, but also destroying the love and hope of the parents. They hope that they can depend on their sons in the future; they grasp any tiny hope that their sons will get rid of the drug one day. But in reality, no one's dream has become true.

3.1.3 Separate Tableware: A Reflection of the Parents thoughts toward “Si Hao Ke”

“When my parents have meals with me, they often separate the tableware from mine or I just eat beside them. I know I am disgusting. They suspect I am infected with some diseases.” (Mr. 7, a 31-year-old, addicted for 13 years)

Separating tableware is the first common reflection of parents. They do not reject drug-taking children but treat them differently because of distrust and averseness. Following is part of a statement from Mr. 22's father. Mr. 22 was the eldest son in his family. His father has sent him to DATC 3 times but none were successful. His father never kicked him out of the family but he was treated differently.

“We do not want to eat together. They are so ugly and make me sick. They must also have some diseases we do not know about. Normally, we cook the same food, but separate the tableware for him.” (Respondent, the father of Mr. 22)

Secondly, although the Dai people are used to throwing away the belongings of the dead, family members will still keep some valuable mementos for memory. Many interviewees stated that they discarded everything that has been used or touched by the “Si Hao Ke”. The room where the drug abusers lived has also been emptied or used as

a storeroom. Following is a section of dialog quoted from Mr. 22's father. Hopefully, it is a good example to show how the belongings of drug abusers are dealt with.

Researcher: "How did you deal with his belongings?"

Respondent (father of a drug abuser): "After he died, we threw away all the stuff that he had ever used or touched, even though some things were still new and useful, such as a mattress, broom and garbage bin."

RC: "Why did you do like this?"

RD: "Because he was very dirty and we wanted to throw away all the bad luck."

RC: "I wonder whether anyone picked up those discarded goods because some of them were still new and useful as you mentioned."

RD: "Yes, other 'Si Hao Ke' picked them up. They used them again or sold them in other communities, otherwise nobody wants to reuse stuff that belonged to 'Si Hao Ke' before."

RC: "What about his room now?"

RD: "We locked it and no one wants to use it any more."

3.1.4 Life without Sex

Among the 24 informants, 13 of them have never been married, 8 of them were married and remain married and 3 of them were abandoned by their wives after drug abuse. (See table 5-1)

"I wanted to be married before but after I took 'Si Hao', I have given up this idea because I know no one wants to marry me, a 'Si Hao Ke'. I have never had a girl friend." (Mr.24, a 30-year-old, addicted for 12 years)

"After taking 'Si Hao', I have never wished that I could be married one day. But my drug friends told me that the feeling of using drugs is more exciting than touching a lady." (Mr.8, a 32-year-old, addicted for 7 years)

As Mr.24 and Mr.8 mentioned above, most respondents revealed that if people abuse the drug early on, they will be unmarriageable even having no girl friends because nobody is willing to have a relationship with a drug abuser. In addition to marriage,

there are no sex workers in this community and drug abusers are not able to afford commercial sex services, so most of them have no experience of sexual intercourse at all.

In this community, “Si Hao” is also called “Si Xiao Jie” (No. 4 beauty) meaning that heroin is more beautiful and attractive than women in general to drug abusers. As long as they rely on it, women are not important in their lives anymore.

Even though there were 11 informants who have been or were ever married, I was amazed by what the respondents told me, because marital relationships were different from people in general and the meaning of “Si Xiao Jie” can also be proved.

First of all, I noticed that 3 of the 11 informants were abandoned by their wives after taking heroin, so I asked specific questions to understand the reason. Here, I will just quote one conversation with Mr.12 as an example. Mr. 12 got married at the end of 1995 but his marriage was only maintained for 1 year because he started using “Si Hao” in 1996.

RC: “When did your wife leave you?”

RD: “One year after I used ‘Si Hao’?”

RC: “Do you have any children?”

RD: “No, we don’t have any.”

RC: “Why did she leave you?”

RD: “I did not ask but I think she could not tolerant my behaviour.”

RC: “Did you beg her to stay?”

RD: “No. In fact, I was not informed that she was leaving.”

RC: “After this, have you been with another woman?”

RD: “Never. Nobody is willing to live with me.”

RC: “What about yourself? Do you want another woman?”

RD: “No, I don’t. I don’t have any desire to sleep with a woman after a period of taking ‘Si Hao’.”

Another two informants (Mr. 2 and Mr. 25) also have similar experiences to Mr.12. In addition, these two wives not only abandoned their husbands but also abandoned their children in order to break away from drug-taking husbands.

Secondly, only two informants got married after heroin abuse. I wonder why those two women were willing to marry them. After hearing their statements, I found: Mr. 15 and his parents hid his status from his wife when they were married because he is the only child in this family, so he should carry on the ancestral line; Mr. 21 has been abandoned by his ex-wife. The present wife is a drug dealer. She got married to deceive the public.

Lastly, both parents and wives I interviewed mentioned that most of the wives of drug abusers have not had sex with their husbands since they used heroin in spite of the fact that they still maintain the marriage. Averseness to dirtiness and ugliness, and fear of being infected with an infectious illness and an unbalanced state of affection are common reasons for nonaccess.

“Since he started to use ‘Si Hao’, I had never slept with him. He has slept alone and I have slept with my daughter.” She also mentioned other reasons: “I loathe him. He just need money and drugs everyday...He was so dirty and sickly that I did not want to be close to him or touch him...I heard from a television program that ‘Si Hao Ke’ are more likely to get diseases. To protect myself, I refused to sleep with him any more. Moreover, I found his desire was not as strong as before. He has never asked me forwardly. Thus, we also believe the ‘Si Xiao Jie’ meaning ‘Si Hao’ is more tempting than women...As far as I know, many wives of ‘Si Hao Ke’ have stopped sleeping with their husbands in our community.” (Respondent, the wife of Mr. 5)

“His wife has requested a separate bedroom since he touched ‘Si Hao’. This is understandable. He is so disgusting and dingy. How could his wife stand that?”(Respondent, the father of Mr. 10)

Apart from sex, the separation of tableware and other utensils has also taken place among the spouses. They provide the food but do not have meals with drug abusers. Antipathy to the dirtiness of drug abusers and the suspicion of infectious diseases are still common excuses for taking these actions.

Mr.13 is the only person I interviewed who reported that they still live together as a “normal” couple.

“I lost my job after using the drug. My wife does not want me to become a thief so she supports my drug use with her salary. I am sorry for her and my daughters so I think I should do something for them to make up for my mistake. I cook for them everyday and we eat together. My wife still allows me to sleep with her.” (Mr.13, a 47-year-old, addicted for 10 years) His wife also confirmed that they still sleep and eat together because he looks clean and treats everyone well.

Table 5-1 The marital status of the informants

Cases	Marital status	Remarks
1	Unmarried	
2	Divorced	Abandoned by wife after drug abuse
3		
4	Unmarried	
5	Married	married before drug abuse
6	Married	married before drug abuse
7	Unmarried	
8	Unmarried	
9	Unmarried	
10	Married	married before drug abuse wife remarried after his death
11	Unmarried	
12	Divorced	Abandoned by wife after drug abuse
13	Married	married before drug abuse
14	Unmarried	
15	Married	married after drug abuse
16	Married	married before drug abuse
17	Unmarried	

Cases	Marital status	Remarks
18	Unmarried	
19		
20	Married	married before drug abuse wife remarried after his death
21	Married	Abandoned by ex-wife remarried after drug abuse
22	Unmarried	
23	Unmarried	
24	Unmarried	
25	Divorced	Abandoned by wife after drug abuse
26	Unmarried	

3.1.5 Abusing “Si Hao”, Abusing the Wife

Drug abuse not only breaks the heart of parents but also tears at wives’ feelings. Wife abuse is a potential problem and has been pointed out by many respondents indirectly, especially by three investigated wives. They suffered both emotional pain and physical assault.

Mr. 6 had used the drug for 15 years and died last year. His wife, 42 years old, has 2 daughters. She sells bean curd for a living. She is easy-going and talkative. When we talked about the heroin history of her husband, her voice shook with emotion. “He had used ‘Si Hao’ for 15 years and hurt me for 15 years. Before taking ‘Si Hao’, he was an employable husband but he was totally changed by using ‘Si Hao’. He just asked for money everyday. If I did not give him any, he would curse at me and even beat me. I tried my best to help him abstain from taking heroin heaps of times. Once, I heard there was a good addiction treatment center in Myanmar so I borrowed some money from relatives and climbed the mountains on foot for 3 days accompanying him. I just hoped that he could abstain from drugs. However, after we came back from Myanmar, my husband used drugs again. I despair of ever seeing the dawn.....I have suffered for 15 years. I never slept well during these 15 years but I had to be strong for my children. After he died, I feel at easy and I am happy now.”

When I saw Qian (Mr. 16’s wife), I was open-eyed because a broad scar across her cheek. After the interview, I knew her face was scarred badly but

her heart was scarred deeply as well. “He became crazy after using ‘Si Hao’, especially when he was dying to use it, his temper was uncontrollable. If I did not give him money in time, he would slap, kick or beat me. One day, I did not have any coins in my pocket so I could not give him any money. He slapped me again. A few minutes later, he suddenly picked up a bottle of kerosene and broke it over my head. When I realized what was going on, it was too late because my hair, any face was burning.”

As in the above tearful stories, wife abuse happens among drug abuser’s families due to the uncontrollable desire to take heroin. It can take many forms, including hitting, slapping, kicking, and beating. Sometimes, it may be accompanied by verbal abuse, psychological abuse, and threats or acts of destruction towards the wife and personal property. Such violence affects all aspects of women’s lives, their health, productivity, and injuries (ranging from cuts and bruises to permanent disabilities).

3.1.6 Pitiful Orphans

Under this subtitle, I would like to stress the impact of drug abuse as a problem faced by children. There are several issues in this line of argument. First, the logic of this story is the loss of family and parents’ love. At the moment, there are 15 children who have been orphaned by junkies’ families in the community, but an increasing number of children are losing their families. Although 13 out of 15 children are adopted by relatives or neighbors or are living with grandparents, they should be more independent and improve their ability to care for themselves even their grandparents. For instance, Ms.3 and her drug-taking husband died of AIDS in 2004. Two of their daughters are living alone now. The elder sister (a14-year-old) has taken the responsibility of generating income and producing food so she has left school and works in a restaurant.

There is a lack of support for school attendance, so many children face the problem of school drop-out. This situation can happen in both the period of the fathers' heroin addiction and when orphaned. While the father is taking heroin, the children may not go to school on account of his inability to support the family financially. After being orphaned, financial support is obviously the principal obstacle to school attendance. Nowadays, the Yunnan Women's Federation and the Yunnan Red Cross cooperate with local government to donate the living expenses and tuition fees of orphans so that all the orphans are able to keep studying at school.

Psychological pain is another serious problem for children in junkies' families such as infantile autism (A severe disorder of childhood characterized by withdrawal, a preoccupation with fantasies, language impairment, and abnormal behavior, such as ritualistic acts and excessive object attachment.) and stress. For example, Yao (Mr. 20's son), a 14-year-old, is one of the respondents. His dad was a drug abuser and died 2001. His mother remarried in another province after his father died. He is living with his grandmother now. His grandmother told me he has not said a word to any one for a long time, since his parents left. At the beginning of my interview, it was also hard to open his mouth. By visiting him several times, he eventually shared information with me.

Lastly, I would like to share one of the orphans' experiences which is a vivid example and also implies other underlying problems happening in their lives.

Yun Xiang (Mr. 2's daughter), is 16 years old, and a student in junior high school. When she was 10 years old, she was just able to go to school. Her father died 5 years ago and her mother lives in another province because her mother has remarried since her father died. She has not met her mother again since that time. Now, she is living with her aunt's family. When we talked about her father, she lowered her head and wept. "I hate him, I hate the 'Si Hao Ke'. If it was not for his behavior (the drug abuse), my mother would not have left me and I would still be at school and I would have an intact family.

In our community, everyone hates them because they are thieves and disturbers of the peace.....Now, I can still go to school to study. I get support from the Yunnan Women's Federation. The school has also reduced the tuition fees for me. Teachers, and classmates treat me very well, they never laugh at me. In contrast, they are always helping me if I have a problem. I really appreciate all the people who have supported me and taken care of me. Therefore, I think I should study hard to repay these people....." I have visited her several times and we have become good friends. I was so surprised with what she finally told me: "I am not very happy. I feel special and different from other children because a lot of outsiders come and visit me. I know they are warmhearted but it makes me feel nervous and different. I am also not happy living with my aunt's family, even though she treats me well. She has no fields or job so she has to depend on my uncle. My uncle is not as good as everyone thinks...One day, when my aunt and her son were out of the house, my uncle crashed into my room and wanted to take off my clothes. Although I finally escaped from the house, I was really scared. I do not dare to tell my aunt.....If possible, I want to leave here after graduating from junior high school....."

3.2 Living in Isolation in the Community

3.2.1 Making a Living from "Si Hao"

The Dai people are a laborious ethnic group. As mentioned above, everyone including women, men, elders and young people should fulfill their duties and contribute to the family and community. For farmers, they must work hard in the field, which is also the major source of income. If lucky some earn extra income by taking full-time jobs or part-time jobs else where. Among the 24 cases (not counting the 2 female cases of PLHA who got HIV through sexual contact), 19 people were farmers before taking heroin, now they do not work for their own families anymore because of no benefits. Indeed, some of them have sold their fields in exchange for money. There are only 5 people who have had formal jobs in a power plant, school or governmental department. Nevertheless, these 5 people have been kicked out since they started to use the drug (See Table 5-2).

"Money" and "drugs", the twin requisites are rooted in the heart of drug abusers after taking heroin, so they must try their best to make a living from drugs. There are 4 kinds of experience mentioned by respondents. First of all, almost all the informants have experienced stealing which is taboo in the Dai community. However, for drug abusers, this is an easy way to get money. Most of them steal everything they can from their own family, and also steal goods from neighbors.

Mr. 9 started using heroin in 1989 and died in 2001. During those 12 years when he was using the drug, his mother could not live any day without worry. She spoke with tears: "I could not keep anything in our house. One day, I had to attend a wedding ceremony so I needed to change my dress. When I opened the cabinet, all of my skirts had disappeared. I knew they must be stealing to exchange for money. As a result, I had to borrow money to redeem my skirts from the neighboring community. Finally, I had to move every valuable goods from my house to a neighbor's house. You may not believe that I had to go to my neighbor's house to get rice to cook everyday during that time, otherwise I would have died from starvation." (Respondent, the mother of Mr. 9)

Mr. 11's father, a 66-year-old, was a teacher in a primary school. He has 4 sons and 3 of them were drug abusers. Mr. 11, the forth son, died in 2002. When I talked with his father, his father was always sighing: "from his eyes, you can only see money and 'Si Hao'. He asks for money everyday. If we do not give him any, he steals everything he can from our house, such as rice, pigs, eggs, and even washing powder..."(Respondent, the father of Mr. 11)

Stealing inside the family has an advantage over stealing outside the family because the thieves will not be punished or beaten and the reputation of the family will be maintained. Therefore, to avoid stealing outside the family, family members such as the wife and parents prefer to support drug abusers, especially those family members who have the ability to afford the drug costs.

Mr. 5 and Mr. 6's wives make a living by selling food in the market. As respondents, they revealed that they gave their husbands (Si Hao Ke) enough money everyday before they went to the market for their business because

they did not want them to be thieves. Mr. 10's wife has become a drug dealer to support her husband. She would rather be arrested by the police than allow her husband to become a thief.

Mr. 13 was a teacher in a primary school but he was fired for drug abuse. Now, he has to depend on his wife because of unemployment. He said: "My wife is a staff member in an agricultural bank. After I was addicted to 'Si Hao', she gave me money everyday in case I would steal something from our neighbours or family."

Besides stealing, two informants have sold drugs to their drug-taking friends while abusing heroin, because they can make a profit for their own heroin use. Not many drug users can do this business, since it requires a sum of money for the first investment.

Here, I will just quote Mr. 18's story told by his mother as an example. Mr. 18 used "Si Hao", when he was 14 years old. This was 14 years ago. He was arrested in 2001 for selling drug. His mother stated: "My son never stole outside the family and he just asked for money from me. One day, he promised he would not ask for money anymore if I could give him the money earned by selling one pig. Later on, I realized he used the money to establish his drug business in order to fulfill his own needs..." (Respondent, the mother of Mr. 18)

"Dr. Xie" is the nickname of Mr. 10. He started using "Si Hao" in 1989 and died in 2001. By listening to his story from his parents, I further understood the "Si Hao Ke" are able to afford drugs from the above-mentioned sources. "Xie was good at venipuncture and he could even inject heroin into the vein of his penis, so drug friends called him 'Dr. Xie'. Hence, our family house became a venue for 'Si Hao Ke'. He just thought about money and heroin everyday. If we did not give him money, he would steal everything from our house. Later on, his wife had to sell heroin to support him because she didn't want him to steal from others. Afterwards, his wife was arrested by the police. During the course of her imprisonment, Xie helped drug friends to perfect and inject heroin in order to exchange heroin with him."

Being a farmhand or a labourer is another familiar way to earn a living. In the busy farming season, some families which have a lack of labor have to hire extra labor

for field work. However, as mentioned in chapter IV, general community members not only need to work with their own family but also work with neighbors or relatives as extra laborers. Thus, drug abusers become available farmhands. Most drug abusers prefer this way if they have the chance because they can earn legitimate money. Moreover, sometimes drug abusers are hired as short-time workers by restaurants or other institutions. Even though drug abusers can take short-time jobs to earn legitimate money, they are treated differently and unequally from general workers.

“Few master work together with us. They just supervise us or work in the side field. Moreover, we never eat together.” (Mr.15, a 34-year-old, addicted for 10 years)

All the drug abusers interviewed by me have the same experiences as Mr.15. Dr. Li also told me: “Yes, people still give work opportunities to ‘Si Hao Ke’ but you should realize that most of the jobs they do are not acceptable to general people or are paid lower salaries.” An owner of a restaurant confirmed that she just hires “Si Hao Ke” to conduct tasks such as chopping firewood and she throws away or sterilizes the tableware that has been used by “Si Hao Ke” workers. One day, I met Mr. 12 while he was cleaning excrement from the toilet cesspool. This is a dirty job which was reluctantly done by general community members. He spent the whole day to finish this job and he just earned 3 dollars.

With heroin abuse, drug abusers will take any possible chance of getting money, no matter how bad the job is or how people treat them. After I interviewed Mr. 7, he said: “can you give me 10 RMB and some medicine?” “Why do you need money and medicine?” I asked. “I need money for food and medicine for my wound.” I understood what the meaning of food was so I did not question this closely. I just asked “why do you have a wound?” “Hey.....I was beaten for stealing.”

Table 5-2 The work experience of the informants before and after drug taking

Cases	Work Experience Before Heroin Use	Work Experience After Heroin Use
1	Farmer	Stealing/Farmhand
2	Farmer	Stealing/Farmhand
3		
4	Farmer	Stealing/Farmhand
5	Leader of the village	Jobless/Farmhand/dependent on wife
6	Farmer	Dependent on wife
7	Farmer	Stealing/Farmhand
8	Worker in a power plant	Jobless/Stealing/Farmhand
9	Farmer	Stealing
10	Farmer	Stealing/Dependent on wife (drug dealer)/Helps of other drug abusers
11	Farmer	Dependent on father
12	Army/worker in a power plant	Jobless/Stealing/Farmhand/Laborer
13	Teacher	Dependent on wife
14	Farmer	Stealing/Farmhand
15	Farmer	Farmer
16	Farmer	Farmhand/Dependent on wife
17	Farmer	Stealing/Farmer
18	Farmer	Stealing/Drug dealer
19		
20	Farmer	Stealing/Farmhand
21	Farmer	Dependent on wife (drug dealer)
22	Farmer	Stealing/Farmhand/Drug dealer
23	Government staff	Jobless/Stealing/Farmhand
24	Farmer	Farmhand/Dependent on parents
25	Farmer	Stealing/Farmhand
26	Farmer	Stealing/Labor/Dependent on brother

3.2.2 Being Isolated from the General Public

In this community, there is no obvious social stratification among people except for more respect for the elder generation. However, “Si Hao Ke” are isolated as an inferior social group from people in general. Although they are not banished from

society, they are an isolated social group established within the society. “Hao Ren” means good men and is used to indicate non-drug users and a difference is made between “Si Hao Ke” and “Hao Ren”. This manifestation of such isolation from daily communication, social activities as well as the workplace were identified and reported by drug abusers and their family members.

“Since I touched ‘Si Hao’, my friends have rarely kept in touch with me except ‘Si Hao’ friends. I know they look down on us so I also avoid contacting them from my own initiative. I just play with my ‘Si Hao’ friends because nobody looks down on me and nobody cares who I am.” (Mr.12, a 35-year-old, addicted for 8 years)

As mentioned before, many of Mr. 26’s family members have died. Now, only he and another elder brother are alive. This brother is a non-drug user and works for the local government. When I heard Mr.26 was just released from jail, I went to his room and interviewed him. “I just came back from jail, my parents and 2 elder brothers died many years ago. Only 1 brother and his wife are living here now so I live in this room alone...I have to make a living for myself despite my brother providing some food and articles for daily use. I work as a farmhand in my community or neighboring community. In the field, I also work alone. I never contact others because I know they look down on me...After work, sometimes, I go to a public amusement room to watch TV but I do not dare to sit down, I just lean against the door or crouch near the gate...I also do not dare to visit my brother because I worry about gossip among his colleagues...” (Mr.26, a 26-year-old, addicted for 10 years)

Aunt Yun’s family is a large family. She has raised 6 sons. In the past, many relatives visited her house frequently. They told me it was a harmonious and lively family. Unfortunately, 4 of the 6 sons are addicted to heroin. She continued: “now, even the dog has stopped barking in front of our house because so many ‘Si Hao Ke’ are here.”

All the respondents, either drug abusers or family members that I interviewed also mentioned that “Si Hao Ke” rarely attend any social activities. In this community, common social activities are wedding parties, funeral ceremonies, religious activities

and festivals. As mentioned above, people are used to getting together and hold dinner parties during celebrations.

When I visited Mr. 17's family, a neighbor had sent an invitation to a wedding party to his mother. Then I asked his mother whether Mr. 17 had ever attended this kind of activity with her. She answered: "'Si Hao Ke' rarely attend wedding parties or funeral ceremonies because they are afraid of being looked down on by others. One day, I brought my son (Mr. 17) with me to attend a wedding party. We were embarrassed because nobody was willing to share a table with a 'Si Hao Ke'. He just sat around with other 'Si Hao Ke'. From that time, I have never asked him to attend this kind of union anymore." (Respondent, the mother of Mr. 17)

The participants of the focus group discussions also confirmed that they never shared a table with "Si Hao Ke" at any dinner party and the tableware used by the "Si Hao Ke" must be separated and later boiled. One male participant said: "many of my friends are involved in 'Si Hao' but we broke our friendship after using 'Si Hao'. Now, if I meet them anywhere, I still say hello to them but we have no further contact. For instance, I never smoke cigarettes offered by them."

To understand the reasons why people treat drug abusers in this way, I questioned both drug abusers and non-abusers.

"I think people dislike us because we are so dirty. Everyday, we are concerned with money and "Si Hao". We do not care about other things even our personal appearance, so we hardly take baths. Moreover, people are afraid of us stealing and borrowing." (Mr.12, a 35-year-old, addicted for 8 years)

"Yes, we dislike them because most of them are disgusting and sickly. In addition, they are always stealing in our community or borrowing something from others but never returning it. Hence, we don't want to be bogged down."(Key informant, a non-abuser)

3.2.3 Friends

As can be seen from above mentioned situations, social isolation may reflect the broken friendships between users and nonusers. Thus, drug abusers can only make friends with other drug abusers. The same experiences of heroin taking, loneliness and their social status group them together. Most respondents mentioned that they feel comfortable and easy-going, when they stay with drug friends. However, “drugs” play a particular role in such relationships. On the one hand, they look for understanding from each other, sharing drugs seems the main purpose maintaining such relationships. On the other hand, the existence of such a friends’ network is the major reason for drug abusers relapsing.

“I have been to DATC several times but I could not stop taking it. After I came back from DATC, I felt lonely, no one really understood me except my ‘Si Hao’ friends, so I had to contact them and relapsed again.” (Mr.12, a 35-year-old, addicted for 8 years)

“He just has ‘Si Hao’ friends. After he came back from DATC, I knew if he contacted them, he would try ‘Si Hao’ again so I had to stay at home everyday and watch him in case he contacted them once more. But it was not convenient after a long time so finally, I begged a policeman to take him away and put him in jail. I hope it works because he will be imprisoned for 8 years, namely he can keep away from those friends for 8 years.”(Respondent, the mother of Mr.18)

A lack of understanding from non-drug users in society has pushed them to look for comfort from their peers. This situation not only keeps them involved in drug abuse but also reinforces the social status of the “Si Hao Ke” group.

3.2.4 The Death and Funeral of a “Si Hao Ke”

Death is perceived as a release for drug abusers and family members. Neither parents nor spouses felt sad or depressed by the death of “Si Hao Ke”. In contrast, most respondents used the words--free, easy, happy and unattached to describe their feelings after a “Si Hao Ke” died. They also think that death is the only release for a “Si Hao Ke” from heroin. Furthermore, death is not only regarded as an end but also as a beginning because people can pin their hopes on the next life.

Mr. 6 died in 2003. His wife talked about his death without any sadness because she was disappointed with her drug-taking husband. “I was not sad at the time when he died. I thought it was a good end for him and me. I still held a great funeral party for him because I thought if I treated him well this life, he would not annoy me in the next life.”(Respondent, the wife of Mr. 6)

Mr. 4’s father is 62 years old. He is famous for his special skill of arranging for funeral ceremonies. He made special arrangements for the funeral ceremony of his son. “My eldest son was a ‘Si Hao Ke’. He has used ‘Si Hao’ for 20 years since he was 20 years old. I was disappointed in him so I hoped he could be released by ending his life...He has never been married so when he passed away, I made an imitation wife for him. I hope he can be free from ‘Si Hao’ and married in the next life.”(Respondent, the father of Mr. 4)

According to traditional customs, the funeral is an important ceremony for everyone in the Dai community. Every respondent said that they still held great funeral ceremonies for “Si Hao Ke” based on traditional customs and all the relatives and neighbors also attended the ceremony. However, nobody, even family members are willing to touch the corpse. According to ritual, the corpse must be washed and wrapped in calico before being put in the coffin. In terms of cultural beliefs, the death of a “Si Hao Ke” belongs to ominous deaths, not only because most drug abusers are less than 60 years old but also because they died from deviant behavior. People fear

getting bad luck from them so nobody wants to wash and wrap the body of a “Si Hao Ke” or carry the coffin.

This information was confirmed by many families of drug abusers. For example, Mr. 11 died of pulmonary disease after 10 years of using the drug. Mr. 11’s father said: “When my son died, I held a great funeral party for him with many relatives. But nobody was willing to wash the corpse or carry the coffin so I had to hire some ‘Si Hao Ke’ to do it.” (Respondent, the father of Mr. 11)

Almost all of the respondents revealed that they just hired other drug users to conduct these jobs. Moreover, many respondents mentioned that the drug abuser’s body can not be buried in the ancestral grave area and a special place is divided for them in case their spirits influence the ancestors and offspring. At first, I could not understand what this special place was and how it was different from the ancestral tomb, so I asked one villager to show me. After observation, I totally understood. For the ancestral tomb was built of stone with a visible tombstone. It was easy to identify who was buried in the grave. In contrast, at the “Si Hao Ke” burial ground, I could not distinguish where the grave was and only small mounds towering above rubbish or decay could be recognized. I have to say that the same background the group shared together was isolation when they were alive, but they are still bound together as sinister ghosts in the under world.

3.2.5 Religion and “Si Hao Ke”

In the contemporary Dai community, both Hinayana and primordial religion exist. According to the Hinayana doctrine, drug abuse is taboo but monks and people seldom talk about this issue in Buddhism in the community. Usually, only elder men and married women attend Buddhist activities. Being youthful men, “Si Hao Ke” hardly attend any Buddhist ceremonies but their family members are still doing “Bai” for “Si

Hao Ke” and for themselves. They always hope that “Si Hao Ke” can be “Hao Ren” (good people) in the next life and their family can be free from “Si Hao”.

For the rituals in the primordial religion, because “Si Hao Ke” have already been isolated from people in general, they rarely participate with other male villagers. They just go alone or with drug-taking friends. Meanwhile, the doctrine of the primordial religion also excludes drug abuse. The interviewed shaman told me: “the Dai people believe in destiny so they often ask me to do fortune-telling. But nobody asks me to do this job for ‘Si Hao Ke’. In addition, normally, people ask me to pray for the soul of a deceased person but few people ask me to do so for ‘Si Hao Ke’. I believe that ‘Chi Si Hao’ is not a fate, it is an individual choice. Anything caused by ‘Chi Si Hao’ is a deserved result.”

3.2.6 The Coping Strategies of People to “Si Hao” and “Si Hao Ke”

To prevent deterioration into heroin abuse in the community, local people have adopted a series of strategies. First of all, the regulations of the village were revised and added to in terms of drug abuse. I have reviewed newly effective documents which show the punishment for “Si Hao Ke”. If anybody becomes drug abuser, he will:

- have private fields confiscated for the public treasury;
- be deprived of rights which community members have;
- be dismissed from youth groups;
- be fined 200 RMB if stealing in the community;

For general villagers, they are not allowed to buy anything from “Si Hao Ke” and they will be fined 200-300 RMB if they receive or accommodate any foreign “Si Hao Ke” or “Si Hao” dealer.

Moreover, as mentioned in chapter IV, in this community, a special team made up of governmental officials and villagers was established to cope with the drug problem. They advocate prohibition of the drug among the young generation as well as organizing one month abstinence campaigns every year. Incidentally, during the period of my data collection, this one month abstinence campaign was conducted. While diffusing information on the harm of heroin, an abstinence camp was set up for all the drug abusers. They must stay in a special place and be supervised by guards. I have visited this special place. 5-10 drug abusers shared one room and each person was allowed to bring only one mattress and a quilt. Mr. 12 told me: “they are very strict with us. Nobody can go out and only parents or spouses are allowed to come in to deliver food. One day, we could not control ourselves so I planned to escape from here for a while. Unfortunately, I was rearrested by them and they hit me hard until I could not stand up.”

3.2.7 The Lives of Family Members of “Si Hao Ke”

Heroin abuse has changed drug abusers’ lives from the “normal” life style, which has strong reflections on the way that community members treat them. Generally speaking, this condition may embroil junkies’ family members in similar judgments, contentions, or hostile actions from people. They may also suffer from isolation, stigmatization or discrimination. Hence, I also collected the data on the lives of drug abusers’ families in order to further understand the real situation and extent of stigma. Surprisingly, all the family members of drug abusers still maintain a “normal” life style as general villagers: parents are taken care of by other children, admitted by relatives, treated and helped by friendly neighbors; the wives are given sympathy by other women and they can feel free to attend any social activity, to sell food in the market, to remarry with non-drug users; non-drug-taking brothers receive equal respect from people and they are still able to play, and work together as brethren. They

can also feel free to set up new families with lifelong spouses; the children of “Si Hao Ke” can go to school to study without derision or teasing, instead, they receive a warm welcome and concern from neighbors, classmates and teachers. Following are the original statements from several family members of drug abusers:

“Although my son was a ‘Si Hao Ke’, my life is the same as other people. They still respect me and invite me to attend wedding parties or religious rituals.”(The father of Mr. 4)

“Now, I am really enjoying my life. My bean curd is very famous so I can earn enough money for me and my children. Nobody looks down upon me and they treat me well. I also want to remarry with a ‘good’ guy.” (The wife of Mr. 6)

“Xie’s wife remarried with a governmental official after Xie died. Although, her ex-husband was a ‘Si Hao Ke’ and she had to sell ‘Si Hao’ to support him, her new husband treats her well. We are so glad that she is happy with her new family.” (The parents of Mr. 10)

Xia married Mr. 18’s brother, she told me: “I do not care about his brother who was a ‘Si Hao Ke’, I just care whether he is a ‘Si Hao Ke’. His brother was using ‘Si Hao’ but this is not his fault, nor his family’s fault. I love living with them.” (The brother’s wife of a drug abuser)

In the focus group discussions, people also reflected that they never looked down upon or blamed family members of “Si Hao Ke” because they are inculpable. Nobody forced anybody to be a “Si Hao Ke”, which is an individual choice and unrelated to other issues.

Even now, I have to point out that the negative impacts of drug abuse on families are obvious such as poor living conditions, and physical and psychological suffering as previously mentioned, especially for elders and children regardless of the normal responses of people to those families.

4. The Reactions of the “Si Hao Ke”

As can be seen from the above description, The “Si Hao Ke” are often associated with stealing, cheating and being dirty which are regarded as their common features. They are labeled as deviant and put in an inferior position in society arousing the negative treatment from people in general. To respond to such different treatment, the “Si Hao Ke” have several attitudes and reactions.

4.1 Deserved Treatment

Basically, the “Si Hao Ke” also hold similar opinions to general people to look at themselves. Most of them think their behavior upsets the social order, and disturbs other people’s lives so they hold a positive attitude to judge this unusual treatment, which is reasonable and acceptable to them.

“I never blame others. If I did not become a “Si Hao Ke”, they would not treat like this. We often steal and cheat other people for money, so no wonder people do not want to have contact with us. I deserve it.” (Mr.12, a 35-year-old, addicted for 8 years)

“It is nobody’s fault to receive such treatment. Even I myself look down upon a “Si Hao Ke”, though I am also one of them. We have done many wrongdoings to people and family. We hurt them deeply. If I was not ‘Si Hao Ke’, I would treat them the same way.” (Mr.13, a 47-year-old, addicted for 10 years)

The majority of the drug abusers I interviewed think the reaction of people in general is understandable. They do not complain too much and receive it silently. Meanwhile, some of them react outwardly in order to keep a little self-esteem.

“I understand why people isolate us. I do not go to my neighbor’s family, I ask my parents to separate my tableware forthright. I know they are fed up

with us. We are always doing bad things to them, so I take action in advance otherwise I may be embarrassed if they ask me.” (Mr.24, a 30-year-old, addicted for 12 years)

As mentioned before, Mr.26, one of the respondents, does not dare to take a seat in public and avoids contacting his non-drug-taking brother in the workplace. When I asked further questions as to why he holds such behavior, he explained: “I know people dislike me, so I feel more comfortable if I do what they want me to do first.” (Mr.26, a 26-year-old, addicted for 10 years)

Despite drug abusers being treated unequally from mainstream society, these respondents show a tolerant attitude to the stigma and discrimination while grasping at their self-esteem, which is common to “normal” people.

4.2 Self-approval

Nevertheless, one interviewed drug abuser’s opinion was quite different from others. He does not show his understanding of this unusual treatment, instead, he ignores the perceptions and responses of others and even displays the attitude that drug abuser is a superior experience.

I met Mr. 21 at the abstinence camp. He has used “Si Hao” for 15 years. When I interviewed him, he was always looking at the ceiling of room. “Why should I blame or blush myself? I chose ‘Si Hao’ which is my business, it is not related to others. I do not care how people look at me and how people treat me. I just do what I like to do. Who said ‘Chi Si Hao’ is bad. How many people have tried it in the world? Only senior people are able to try it.” (Mr. 21, a 35-year-old, addicted for 15 years)

One respondent, the mother of Mr. 18 also told me: “he has lost his sense of shame. He never cares about the comments and judgments of people. He said ‘Chi Si Hao’ is superior to ‘Chi Rou’ (eating meat) and it is a pity that I can not try it in this life.”

4.3 A High Sensitivity to Being Stigmatized

However “Si Hao Ke” look at themselves, they are afraid of being stigmatized. They are very sensitive to what people think of them and how people react to them. Dr. Li told me:

“They are highly sensitive to being stigmatized. They always notice what people say and what people do around them. Many times, when they come to see me with wounds, I am used to wearing gloves to clean the wound, but they often ask me why I wear the gloves and whether I discriminate against them. Sometimes, when they take intravenous injections in the health center, there is no bed available so I ask them to sit down for the injection but they say I discriminated against them and treat them unfairly. In addition, some people do not want to lie on a bed which has been led on by a ‘Si Hao Ke’ so I have to change the bed sheet after a ‘Si Hao Ke’ has used it. However, they also complain about my behavior.”

During my interview, I also noticed that drug abusers are concerned with my behavior very much. They pay attention to where I sit, what I express and what I react to with them. For example, one day, I met Mr.24 in the health center by chance so I did my interview in a private room at the health center. At first, I sat on the bed which was opposite his seat. It seemed as if he was uncomfortable and reluctant to answer my questions at that time. And then, after I shifted my position to his side where we were close together and shared some candy with him, he became another person, talkative and easy-going.

4.4 Revenge

“...Do you know? Although we look down upon ‘Si Hao Ke’, we never dare to talk about them in their presence, unless the ‘Si Hao Ke’ is a blood relative. Sometimes, we see them using ‘Si Hao’ but we must pretend that we didn’t see them and keep away from them otherwise some of them will take revenge

on us...They may empty our house, beat us or uproot our plants, even destroying our foodstuffs by burning...”

The aforesaid description is a quote from a focus group discussion. I was shocked, when I heard these awful statements. I could not believe they happened in this community, so I confirmed them with Dr. Li and other villagers but they were rare cases.

Dr. Li reiterated: “yes, few ‘Si Hao Ke’ make aggressive reactions to people. As I told you before, they are very sensitive to what people say and do. They may take revenge on people who are not their blood relatives if they censure them or report them to the police. Let me tell you two stories. As far as I remember, one village leader gave the ‘Si Hao Ke’ a lecture to persuade them to stop but he never thought that the plants of his family would be uprooted the next day. Another village leader reported a ‘Si Hao Ke’ to the police so that the ‘Si Hao Ke’ was arrested and taken to the DATC. After his release, the ‘Si Hao Ke’ killed him. But do not be scared, not all the ‘Si Hao Ke’ are like this, only a few are crazy.”

As a matter of fact, given the widespread negative community responses, many “Si Hao Ke” are afraid of being marginalized by mainstream society so they may be reluctant to acknowledge their identity and social status, but few of them complain for fear of negative or hostile reactions.

CHAPTER VI

STIGMA AND DISCRIMINATION RELATED TO HIV/AIDS

This chapter follows on from chapter V (the lives of “Si Hao Ke”) because we could not really understand this issue without understanding the situation of drug abuse in the community. Almost all of HIV transmission results from sharing needles. Only 2 of the 64 infected people are not drug abusers. Apart from showing people’s perceptions of HIV/AIDS, this chapter also shows the responses of people toward PLHA which is tightly linked to the lives of “Si Hao Ke”.

1. Understanding HIV/AIDS

1.1 “A La Xi Ya” and “A La Bing Dong”: the Names of HIV/AIDS

Local people told me that HIV/AIDS is a new disease that has appeared in their community so they do not have an exact Dai name for HIV/AIDS. However, there are three common Dai language terms used to label this disease. The first is “A La Xi Ya”. “A La” means disease and “Xi Ya” means junky, so the combined meaning of this slang is junkies’ disease. The second slang term is “A La Bing Dong”. “Bing Dong” means superficial pustules of drug abusers, and “A La” indicates disease, so the combined meaning is junkies’ impetigo. The last slang term, in fact, is a common term meaning patient: “Yan Dan Bing”, but if it is used for drug abusers, everyone will know this person must be infected with HIV. As these slang terms showing, HIV/AIDS is regarded as “somebody else’s health problem”, and not for all.

Drug abusers as a particular group are inherently at risk of carrying HIV/AIDS and the typical symptom is skin problems-- superficial pustules.²

1.2 A Lack of In-depth Knowledge and Misconceptions

1.2.1 Hearing but Without Knowing

Almost all of the respondents in this study have heard of HIV/AIDS which is an infectious disease. The data shows that the majority of respondents know that the main modes of transmission are through sex and infected blood or needles. Many also know that using condoms can limit the sexual transmission of HIV, and that not sharing needles also reduces the risk of catching HIV. They also mentioned that daily contacts such as eating, hugging and touching will not spread the virus.

In 1992, Mr. 24 became a “Si Hao Ke”. Three years later, he was infected with HIV from sharing needles. He heard the information on HIV/AIDS at the CDPC after being infected. He explained some transmission routes and protection methods related to HIV/AIDS: “I know it is an infectious illness and can be transmitted by sleeping or injecting with someone else...Using a condom, and not sharing needles can protect people.” (Mr.24, a 30-year-old)

Ms. 3 was a female PLHA. She got HIV from her drug-taking husband. Both of them were diagnosed in 2003 and died 8 months after the diagnosis. Since they were diagnosed, their daughters paid attention to HIV/AIDS. The daughter explained: “I know my farther got this disease from injections and my mother caught it from my father because they slept together...When they were sick, my sister and me were not afraid of the infection. We know sharing food and touching is not going to transmit the infection.”(Respondent, the daughter of Ms. 3)

However, the data shows that there is an incomplete understanding of HIV/AIDS

² Due to language barrier, I could not interview people in Dai language directly so I still use HIV/AIDS or disease in my interview.

among the respondents. People know how they or their family members got the disease but they do not know what HIV/AIDS means exactly or what the difference is between HIV and AIDS, how the disease progresses, what the prognosis is and what the longevity of a person with HIV is. Herpes are considered visible and common symptoms, and other symptoms are just summarized as “Bu Hao Zai” (uncomfortable). Only one respondent mentioned mother-to-child transmission routes. Following are some of the statements from respondents:

Mr. 1 was infected in 1993. Now, he is in the DATC for detoxification. His father told me: “I do not know what HIV/AIDS is exactly. I just know my son was infected by “Da Zhen” (injecting heroin). He must have shared a needle with someone else who was already infected. I also know this disease can be transmitted by sleeping together or touching dirty blood. I just heard that a fever is the primary symptom of this disease but I do not know how this disease impacts on the body and whether it can be cured.”(Respondent, the father of Mr.1)

Mr. 14 was the first HIV-positive case in the community but he is still alive without any visible symptoms. He is also in the DATC now so I can only interview his mother. His mother said: “You know, my son was the first person infected with HIV/AIDS in our community. I know he got it from ‘Da Zhen’ and he will never recover from this disease. I wonder why he is still alive when so many of his peers have died from the disease.” (Respondent, the mother of Mr. 14)

Mr. 24 has the longest history of using drugs so he has many drug friends. He was infected with HIV in 1995 but it has not developed into AIDS yet. Although he knows why he caught the virus, he does not understand HIV/AIDS exactly: “I do not know what will happen to me after catching this disease. I just noticed that other infected peers were always saying they were “Bu Hao Zai” (uncomfortable) and I saw some sores appear on their skin.”(Mr. 25, a 51-year-old)

Apart from a lack of in-depth knowledge on HIV/AIDS, some common misconceptions on the relevant knowledge of HIV/AIDS were shared among the respondents.

1.2.2 It is the Result of Using “Si Hao”

“I heard that the ‘Si Hao Ke’ hardly escape catching HIV/AIDS because they are always injecting together...In 1995, I knew my husband had been infected. I was not surprised because I knew it was a certainty for ‘Si Hao Ke’.”(Respondent, the wife of Mr.5)

“I was not surprised by my infection because this is the fate I expected.”
(Mr.7, a 31-year-old)

It is true that many respondents did not show much surprise to drug abusers who are infected with HIV. Both drug users and nonusers think being infected with HIV/AIDS is absolutely guaranteed for drug abusers even though they know sharing needles is a risky behavior which causes HIV transmission.

1.2.3 I am not Going to Get it

Although many see HIV/AIDS as guarantee for drug abusers, some people believe that they can avoid the virus, if they never take heroin. For example, in one focus group discussion held with 5 male villagers, none of which were drug abusers. They know how HIV is spread among drug abusers but they think they are in a safe position, if they never touch ‘Si Hao’.

“I have heard of HIV/AIDS, but only the “Si Hao Ke” are more likely to get it because of ‘Da Zhen’. I do not use ‘Si Hao’, I am not going to get it.”
(Villager, a non-drug user)

“I am not afraid of HIV/AIDS. It will be far away from me if I do not use ‘Si Hao’”(Villager, a non-drug user)

1.2.4 A Skin Disease

Some people think HIV must be symptomatic of the skin. In other words, families and communities are typically unaware as they assume people with HIV show cutaneous problems.

Mr. 18 was identified HIV-positive in 1997. Dr. Li has explained HIV/AIDS several times to his mother but when I asked her whether she knew her son had HIV/AIDS, she still answered: “I do not believe what Dr. Li told me that my son had HIV/AIDS because until now, his skin is so smooth without any pustules or herpes.”(Respondent, the mother of Mr. 18)

Although Mr. 17 died from suicide, he was infected with HIV in 1995, 5 years before his death. His mother never believed her son had HIV/AIDS: “I do not believe that he had HIV/AIDS because his skin was still healthy when he died.” (Respondent, the mother of Mr. 17)

1.2.5 Superficial Pustules are Dangerous

Superficial pustules are considered an obvious symptom of PLHA and close touch with pustules is one way of transmission.

For example, before I visited Mr. 6’s family, I heard from Dr. Li that Mr. 6 had previously displayed serious skin symptoms during the early stage of AIDS. When I asked about preventing the transmission of HIV/AIDS, his wife said: “The pustules were so terrible. I never touched his skin and I did not allow him to hug the children because I think this is an easy way to get infected.” (Respondent, the wife of Mr. 6)

1.2.6 Fat is Safe

Mr.13 was infected with HIV in 1997. His family is the only one I interviewed that still maintains sexual relationships between drug-taking husband and wife. His

wife has never tested her blood because she thinks being fat is evidence of not being infected.

“You see, I am so fat. I think I must not be infected otherwise I would lose weight sharply.”

It is clear that respondents know how HIV is transmitted, but many aspects of HIV and AIDS are misunderstood or missing altogether.

1.3 Health Education: a Source of Information

Almost all the interviewed drug abusers reported that before 2000, they only knew about HIV/AIDS from the DATC or the CDPC after being identified HIV-positive. Family members heard the information on HIV/AIDS from the CDPC when one of their members was infected. Since 2000 when the campaigns on HIV/AIDS were conducted in this community, information on HIV/AIDS has been diffused on wider scale. Dr. Li has worked on HIV/AIDS control and prevention for a long time. She also confirmed: “before 2000, in the absence of HIV/AIDS publicity, people just knew that a person with HIV will die very quickly. Since a series of health education programmes were carried out, most people now understand how HIV is spread, but in-depth knowledge is still sparsely scattered. I think there are three major reasons for this: a lack of intensive and extensive diffusion; a low standard of education among people; and difficulty translating information from Mandarin to the Dai language accurately.”

It is worthwhile to note that health education is an appropriate way to diffuse information on HIV/AIDS, but designing effective health education programs, the availability of pellucid IEC materials relevant to HIV/AIDS, as well as language support for these information networks provides challenges for educators.

2. Stigma and Discrimination Related to HIV/AIDS

2.1 Attitudes toward HIV/AIDS and Individuals with HIV/AIDS

To understand the stigma related to HIV/AIDS, I had to be aware of public attitudes toward HIV/AIDS and individuals with HIV/AIDS in my study. The purpose of my address was twofold---- to present the perceptions of people concerned with HIV/AIDS; to show both the negative and positive attitudes toward individuals with HIV/AIDS.

“Only ‘Si Hao Ke’ are more likely to get this disease. They brought it into our community. We will be safe if we preserve our behavioral integrity.”(Villager, a non-drug user)

This is a common statement from non-drug abusers as the previous description shows, most people believe the “Si Hao Ke” are more susceptible to HIV/AIDS since they have taken heroin, even drug abusers consider themselves inescapable from the HIV/AIDS infection which seems a normal occurrence for “Si Hao Ke”. In addition, some people even thought HIV/AIDS was brought by drug abusers into the community. On the contrary, non-drug users keep away from HIV/AIDS as long as they keep away from drugs so they do not fear this disease.

Apart from these perceptions to HIV/AIDS, my data also demonstrated that people held different attitudes both negative and positive toward drug abusers, women and elderly people living with HIV/AIDS.

2.1.1 No pity, No fear: the Attitudes of People toward the “Si Hao Ke” with HIV/AIDS

It is common sense in the community that drug users living with HIV/AIDS are not pitied as it results from their own suicidal choice---abusing drugs with the addition of associated deviant behaviors such as stealing and cheating. As a matter of fact, nobody sympathizes and cares about the health status of drug abusers. In contrast, most people not only believe that being infected with HIV/AIDS is a certain result for drug abusers but also a good release from addiction.

I have visited the primary school in the community and two teachers were interviewed in depth. Both of them showed the same opinion: “we never sympathize with someone who gets HIV/AIDS from using ‘Si Hao’. They choose to be a ‘Si Hao Ke’ by themselves so no wonder they are infected with HIV/AIDS. We think it may be a good release for them from ‘Si Hao’.”

Many interviewed family members also do not care about the HIV-status of drug abusers. Following is an example showing what family members thought. “In fact, I did not care about his health very much. I just cared whether he could stop using ‘Si Hao’...When he died from this disease, I was not sad and I thought it was a good way for him to end all the suffering.” (Respondent, the father of Mr. 23)

HIV infection is often seen as a punitive consequence of deviant behavior. The “Si Hao Ke”, as an unacknowledged social group with HIV/AIDS, have only got what they deserve. They have also been blamed for spreading the virus to their spouses.

Xiao Hua and her sister (Mr.3’s daughters) lost both their father and mother in 2004 as mentioned before. She expressed a strong negative judgment for her father: “I hate my father, I hate his behavior because using ‘Si Hao’ not only destroyed our family but also caused my mother’s death. My mother worked so hard for our family but my father just knew ‘Si Hao’. When my sister and I knew that both of them had the HIV/AIDS, we were to leave my mother. My father deserved it, but why did he bring it on my mother...” (Respondent, the daughter of Ms. 3)

2.1.2 A Pity but Evitable: Attitudes of People toward the Women with HIV/AIDS

Up to when I conducted my field work, there were only two women living with HIV/AIDS at the study site. Ms. 3 was infected by her drug-taking husband and Ms.19's infection was suspicious of sexual contact with her drug-taking husband or from clients of sexual services while she was working in the city. Both positive and negative attitudes toward these infected women were demonstrated in this study. Most interviewees showed great pity for those who got HIV/AIDS from drug-taking husbands.

“Those women who were infected by their husbands are innocent. They did not do anything wrong but got the disease from drug-taking husbands. It is unfair.”(Key informant, a teacher)

“We sympathize with those women who got HIV/AIDS from their husband. They used to support their family, especially their drug-taking husbands, now, they have got the disease from their husband.” (Key informant, a villager)

Interestingly, as the following description from Mr.6's wife shows, two interviewed wives living with drug-taking husbands expressed different attitudes to those who caught the virus from their husband. They blame those women for not being able to control their sexual desire so that they caught the illness from their husbands.

“If those women had never slept with their husbands as we did, they would not have HIV/AIDS. They borrowed the trouble from their husbands.”(Respondent, the wife of Mr.6)

In addition, most people had a negative attitude to Ms.19 who may have got HIV/AIDS from being a sex worker. In the Dai language, people use “Hai Gun”, which means to sell ass, to indicate sex workers which are really looked down upon by

Dai people. Hence, the HIV-positive “Hai Gun” may be seen as a consequence of sexual wrongdoing. I can not definitely prove this argument because there is only one case associated with commercial sex.

“She has been a ‘Hai Gun’ (sex worker). I do not pity her because she chose her career by herself. She must bear the suffering caused by her behavior.”
(Key informant, a teacher)

2.1.3 Excusable: the Attitudes of People toward the Elders with HIV/AIDS

In a focus group discussion held in one household where five male villagers were participated, all the participants made excuses for elders who were living with HIV/AIDS. Dr. Li also mentioned people easily accept elder PLHA due to their higher social status and the life-spans of elders.

“I think being infected with HIV/AIDS is excusable for elders (over the age of 60) no matter who they are and how they obtain the disease. They are already old, already near the end of life so they should be excused for what they have done.” (Part of statement from a participant)

“If the AIDS patient is elderly, people will accept it. I think there are two reasons. One is a higher prestige for elderly in the Dai community. Secondly, people think elders have already had long lives.”(Dr. Li, a 48-year-old)

2.2 A Notorious Disease: The Responses of the Local Government

Local authorities downplay the epidemic of HIV/AIDS. They are reluctant to acknowledge the severity of drug abuse and HIV/AIDS in the community because of the shame and the fear of ruining the community’s reputation with this ignominious disease. During the period of my data collection, there were scarcely any officers who would accept my interview or provide data on drug abuse. They worried about the

reputation of the community, which would be ruined by the publicity. Dr. Li had previously accepted reporter gathering news on HIV/AIDS and orphans in the community but she was blamed for betraying the reputation of the community to gain personal fame. She stated: “All along, HIV/AIDS has not been paid attention to by some officers who consider HIV/AIDS a notorious disease that cannot be talked about.”

2.3 Taking Care of PLHA without Intimate Contact: the Responses of Community Members

By far, the most PLHA are “Si Hao Ke” in this community but not all the “Si Hao Ke” are HIV-positive and the identities of PLHA have not been entirely disclosed to public. Nevertheless, on the one hand, “Si Hao Ke are suspected as a certain group associated with HIV/AIDS. On the other hand, the “Si Hao Ke” have been ostracized by people who attribute the use of “Si Hao” as described in the previous chapter. So people do not pay attention to the HIV status of the “Si Hao Ke”. Hence, being a “Si Hao Ke”, the living conditions and environment are not different between before and after being infected. In other words, people give the same treatment to all “Si Hao Ke” no matter who is HIV-positive or not.

Dr. Li as the “mother of the Si Hao Ke” has brought attention to the lives of the “Si Hao Ke”. She criticized: “In fact, although the “Si Hao Ke” are suspected of being HIV-positive, the illness does not label them differently. People just hate the ‘Si Hao Ke’ and fight them off so HIV status in their lives is not important.” (Key informant, a doctor)

Mr. 7 started using heroin in 1991. In 1999, he was diagnosed HIV-seropositive so he has a 5 year history of carrying a double identity, namely, HIV-positive and “Si Hao Ke”. When comparing living with “Si Hao” alone and living with “Si Hao” and HIV/AIDS, he said: “for me, being infected with HIV did not make any sense. People still treat me as they used to do. The

identity of being a 'Si Hao Ke' has made a clear distinction between them and me." (Mr. 7, a 31-year-old)

Although people do not pay more attention to the HIV status of drug abusers and perceive HIV infection as a deserved result, people are still afraid of being infected. Here, I would like to emphasize both the positive and negative responses related to HIV/AIDS that I heard from the general villagers. On one side, people try to avoid intimate contact with "Si Hao Ke" such as physical contact, skin-to-skin contact and body fluid contact. The "Si Hao Ke" are suspected of being HIV-positive, so avoiding intimate contact with "Si Hao Ke" may greatly reduce the risk of being infected. Such ideology also reinforces the seclusion between drug abusers and non-drug abusers.

When I asked the question: "how do you have contact with "Si Hao Ke" who are infected with HIV/AIDS? I got the following answers: "Actually, we do not know exactly who is infected, but only the "Si Hao Ke" are more likely to be PLHA here. We try not to touch the 'Si Hao Ke', especially the skin, blood or sputum. I think that the HIV and other diseases they have may not be transmitted to me in this way."(Key informant, a villager)

"You know, actually, I do not care which 'Si Hao Ke' are living with HIV/AIDS because we seldom contact them, so we do not worry about the HIV infection."(Key informant, a teacher)

On the positive sides, no drug abusers living with HIV/AIDS have ever been banished from the community, instead, when they progress AIDS, people always give them and family members help as much as they can, particularly relatives. Local people believe no one can escape illness, so people ought to take care of each other when they fall sick whatever the disease is. This is also a reciprocating courtesy.

This information was confirmed by both general villagers and the families of informants. "When 'Si Hao Ke' were sick or were dying, we were always visiting and giving them food or money for their families. This is normal in our community. Everyone will face similar problem sooner or later so we should take care of each other..."(Key informant, a villager)

“People did come to visit my husband when he was dying. They also gave me some help and comforted me.”(Respondent, the wife of Mr. 6) As Mr. 6’s wife said, many people including relatives and neighbors visited sick people, especially those who were dying.

However, in the course of visiting, people still try to avoid intimate contact with drug abusers, especially those PLHA manifesting skin diseases who are more likely to be excluded by people. Most respondents reported that they extremely dislike those patients with superficial pustules because of the ugliness and fear of catching the disease through physical contact.

For instance, one day, I had a conversation with my hostess. When we talked about the experiences of visiting sick “Si Hao Ke”, she told me: “I visited the ‘Si Hao ke’ when they were sick but I dare not touch them, especially those who had sores on the skin. One day, I visited a patient. There were many sores on his skin with black flies around him. It was so terrible. I never got close to him, and I just stood outside the door watching him.”(Key informant, a villager)

To sum up, the “Si Hao Ke” are a socially deviant group which has been ostracized from the masses. People do not take further negative responses against the “Si Hao Ke” living with HIV/AIDS. Avoiding physical contact with the “Si Hao Ke” is adopted as a good way of keeping people away from HIV infection. Fortunately, no family member has ever been suspected of being associated with HIV/AIDS by people, even spouses. As mentioned before, the family members of drug abusers or drug abusers living with HIV/AIDS are still able to perform their lives as usual. Nevertheless, there were two women living with HIV/AIDS. They were not “Si Hao Ke” and got the HIV infection through sexual contact. How did people respond to them?

For the lady who got HIV from her drug-taking husband, most people not only show their sympathy but also adopt positive responses. When she was ill in bed, many relatives and neighbors visited her family, even my hostess was a visitor.

“She was so pitiful. Her drug-taking husband brought HIV/AIDS home to her, and she had to die of it. Many of us visited her and attended her funeral ceremony.”(Key informant, a villager)

Despite the fact that people made a positive response to her, one argument I have to point out here is. It was just a short period (2 months) from when she was identified HIV-positive to when she died of AIDS. In other words, people did not disclose her HIV-positive status until she had progressed AIDS as identified in the hospital. Thus, we can not be sure whether people would have taken a negative response to her, if her status had been disclosed in the early days.

For the other infected lady, she was looked down upon by people because she had engaged in commercial sex and she did not have good relationships with others due to her personality. One of her sons recalled that few people visited her during the course of her sickness and few people attended her funeral. Dr. Li also confirmed: “She was not a good woman. She was not easy-going and had been a ‘Hai Gun’ so people never cared about her. When she died, few people came. In the end, I had to convince some ‘Si Hao Ke’ to attend her funeral ceremony.”

2.4 The Responses of Social Institutions

2.4.1 From Negative to Positive: the Responses of the Health Center

First of all, I want to talk about the responses of the township health center to PLHA because it is the only social institution in the community which helps PLHA

directly and supplies health care to PLHA. According to my data, although most drug abusers were less considered with their health, the majority of PLHA can access primary health services from the health center when they have health problems. However, on account of the limited financial support and capabilities of health providers, PLHA only receive rudimental and simple treatment such as general medications for colds, diarrhea or headaches.

9 respondents of PLHA reflected that health providers treat them very well including their attitudes and treatment. No health provider had ever refused to provide services to them, instead, they received free service when they could not afford the fees. On the contrary, one PLHA seeking health services of the county hospital was transferred to the township health center because of their HIV-positive and financial problems.

Mr. 16 was infected with HIV in 1997 but he finally died from an accident. His wife recalled the past events: “My husband was crushed by a collapsing wall when he was building a house. It was serious so we sent him to the county hospital where conditions and the quality of care are better. However, when the doctors found he was HIV-positive and we did not have enough money, they transferred him to our township health center. Even though Dr. Li and the other staff treated him well in the health center, he finally died from his wounds.”(Respondent, the wife of Mr.16)

Even though many respondents expressed their gratitude to the professionals in the health center, Dr. Li revealed that her thinking and method of dealing with PLHA had changed from a negative to a positive response with the development of HIV/AIDS intervention programs. It seems HIV/AIDS intervention programs also affect the health providers' behavior.

“In the early days, I was also afraid of them. At first, I intended to set up a special sickroom for them but I rejected this idea because it was too negative. I adopted another strategy: they were just allowed to sit down on chairs but could not lie on the bed when they came to the health center, even when they

mainlined. Fortunately, a few months later, I took on the responsibility for HIV/AIDS control and prevention programs in our community. Since that time, I have gradually come to understand the PLHA and have changed my attitude. I not only dispelled my misgiving and dread but also wanted to do something positive for them. Therefore, I have made the requirement that the staff must provide better treatment for them, the same for people in general. But as you know, we have limited resources and skills so we can just provide primary health care. Sometimes, I have to spend money from my own pocket. Moreover, I am trying to help them solve problems such as family conflicts and education for their children. As a matter of fact, I am glad with what I have done despite the fact that must pay out something.” (Key informant, a doctor)

2.4.2 Reflections on Health Education

Since 2000, HIV/AIDS health education has been carried out in this community. Particularly, the peer education program is a really effective and powerful intervention tool on HIV/AIDS education compared to other methods. As we know, all the peer educators are drug abusers living with HIV/AIDS or the spouses of drug abusers and drug abusers are the target group of the program. It is a good idea to diffuse information and knowledge to people using personal experiences, but it may reinforce the misunderstanding of HIV/AIDS as a junkies’ disease, and affirm people’s deductions that drug abusers stand a certain chance of becoming PLHA, even their spouses may be suspected. Again, such negative impressions aggravate the stigma and discrimination toward drug abusers.

One peer educator, the spouse of a drug abuser said: “people are always thinking we must be infected with HIV/AIDS otherwise why are we the only peer educators. I think if the team of peer educators could be made up of a different crowd, people would not just be looking at the ‘Si Hao Ke’.”

2.4.3 A “Special” Feeling from Policies Related to the HIV/AIDS Test and Surveillance

“I have been looking for you everywhere because I heard from Dr. Li that you would like to visit me...Can we just talk in a private place other than my house? You know, I do not want you to visit me in my house because the staff of the CDPC are always visiting me in my house, which makes me different from other people. My wife’s office is just opposite our house. I fear that her colleagues will gossip, if they see many strangers visiting me.”
(Mr.13, a 47-year-old)

The above quotation is a statement from Mr.13 that I heard before I interviewed him but I was not surprised by what he said as other interviewees also reported the same feeling and worry as him. Despite the contribution of the CDPC on HIV/AIDS control, surveillance and prevention, some interviewed PLHA or drug abusers said that they feel “special” and the neighbors pay them more attention because of the free tests, condoms and service provided by the CDPC. As a local stereotype, people believe that the CDPC is responsible for infectious diseases, especially HIV/AIDS due to its high prevalence in this community. The drug abusers have been branded by the free tests and visiting service the CDPC provides. Therefore, people think HIV/AIDS is just spread among the “Si Hao Ke” and HIV/AIDS is the end for them. Indeed, many orphans also feel “special” and under pressure which they attribute to the many visits of strangers.

2.4.4 HIV/AIDS and religion

Lastly, I would like to talk about religion and HIV/AIDS because it is a significant social institution influencing people’s thoughts and behavior. Based on what I saw in the field, people and monks seldom talk about HIV/AIDS directly in Buddhism, but activities held to release souls from purgatory have been performed by

the parents or wives of PLHA. In the primordial religion area, people believe the cause of prolonged or serious diseases is possession by ghosts. However, HIV/AIDS as a prolonged and serious problem has never been treated with primordial religion methods. The interviewed shaman also stated that he never thought HIV/AIDS resulted from possession but he explained HIV/AIDS is sort of infectious disease that is related to the comeuppance for “Si Hao Ke”.

2.5 Responses of the Family

2.5.1 Care and Support

There is no drug abuser living with HIV/AIDS who has been rejected by his family but they have had regular attendance and support from families when they need help or reach the AIDS stage. As previously described, most families actually do not care about the HIV infection status of “Si Hao Ke” because of the anticipation. It does not hurt the family as much as the drug abuse. Many family members expressed that if the “Si Hao Ke” could disengage from the “Si Hao”, they would be willing to take care of the “Si Hao Ke whatever his HIV-status.

Mr. 1 was identified HIV-positive in the DATC in 1993. Because he could not stop taking “Si Hao” in the DATC several times, his mother was disappointed and finally sent him to jail. His mother said as long as he could get rid of the ‘Si Hao’ after imprisonment, HIV/AIDS is not a big deal and she would be happy to take care of him until he died.

As mentioned before, Mr. 13 seems to have a normal family. He appreciates what his wife and daughters have done for him: “My wife, and my daughters treat me very well. They never reject me or avoid contact with me even though I am HIV positive. When I was in the DATC, my daughters visited me frequently. They just hope I can give up using ‘Si Hao’.” (Mr.13, a 47-year-old)

Two female PLHA have also not been rejected by their families, instead, the children and neighbors looked after them until they died.

“My sister and I took care of my mother, when she was sick. Some neighbors also gave us a hand. We were not afraid of her and tried our best to fulfill her demands in the endgame of her life.”(Respondent, the daughter of Ms.3)

“When my mother and my father were sick, my grandmother, my little brother and I looked after them until they died.” (Respondent, the son of Ms. 19)

2.5.2 Prevention Strategies

Although family members never reject PLHA, they adopt prevention strategies to avoid infection. Separating tableware or articles for daily use is a popular strategy taken by family members, but such measures are not strange in the daily life of the “Si Hao Ke”. In addition, PLHA are not allowed to touch foodstuffs before they are sold at the market; their sputum must be buried in soil...

Mr. 5 died of AIDS in 2002. His wife is a peddler of rice noodles. When Mr.5 progressed to AIDS, his wife took the responsibility to tend him until he died. But his wife mentioned strategies that she took to prevent HIV infection during the period she looked after Mr.5. “I separated our tableware even before I knew he had HIV... When he was sick, I buried his sputum and never touched skin wounds and I never let him touch my rice noodles which I would sell at the market. Even though I was not afraid of him, I wanted to protect myself and other people.”(Respondent, the wife of Mr.5)

Again, I also found that those PLHA who had skin symptoms or whose symptoms appeared on the skin would suffer more and strict defence strategies taken by family members. For example, people try to avoid the patients’ skin; those PLHA are not allowed to hold or carry babies.

2.6 Individual Responses

2.6.1 Disclosing the HIV-positive Status to Family Members

In this community, when a person is diagnosed HIV-positive, the staff of the CDPC will normally inform his/her family members. However, almost all of the interviewed PLHA reported they were willing to disclose their status to families as soon as they were identified, so family members can be prepared for all contingencies of infection. Some of them also expressed that they disclose their HIV-positive status to the community. In fact, people knowing or not knowing does not make any sense to them.

Mr.13 was identified in 1997. His wife confirmed that she knew his HIV status in 1997. "I told them about my infection as soon as I knew. I hope they can take some preventive measures and I try to avoid touching them when I have wounds...they treat me well so I should not spread HIV to them." (Mr.13, a 47-year-old)

"When I knew I was infected, I told my parents directly. I want to keep them informed and I want them to be aware of prevention...if community members want to know my status, I do not mind telling them. Being infected or not, and letting people know or not is insignificant to me. I am already looked down upon because of 'Chi Si Hao'." (Mr.7, a 31-year-old)

2.6.2 Fear of Double Stigma and Discrimination

Because of the double stigma and discrimination, some PLHA are reluctant to expose their HIV-positive status to communities. They ask families and doctors to keep it secret.

Mr.5 had been a leader in the community before he used "Si Hao". He was sensitive about his reputation. Based on his wife's statement, in 1995, he knew he was infected with HIV/AIDS. He told his wife of his HIV status

directly but he asked his wife and Dr. Li to keep it secret. He said he had lost face due to drug abuse so he did not want to face more humiliation.

Indeed, one respondent (Mr.21) attempted to deny his HIV-positive status. Before I met him, Dr. Li warned me that I should avoid talking about HIV/AIDS directly to him because he is very sensitive about this disease. He was always falling out with the person who mentioned HIV/AIDS. In our conversations, I have to use the term “Bing” (general illness) instead of “HIV/AIDS” and he was reluctant to talk about any issue related to HIV/AIDS.

2.6.3 Avoid Spreading the Virus

Whatever PLHA disclose or deny about their identity, almost all the respondents hold a common opinion that is avoid spreading the virus to others. Besides protecting family members with the above mentioned strategies, they also protect peers by not sharing needles. Alleviating their sins is the main reason contributing to this opinion.

Although Mr.7 does not care about his health, he avoids spreading HIV to others even his drug friends. He explained: “Now, I always carry my own needle and never let my friends use it. In my family, I ask my parents to separate my tableware forthright, because I do not want to spread my disease to anyone. I have done many wrongdoings so I cannot keep making more mistakes.” (Mr.7, a 31-year-old)

Some family members also confirmed that IDUs have tried to protect other people from HIV infection after knowing their HIV-positive status. For example, Mr.1’s father told me: “He was reluctant to share needles with drug friends after he was diagnosed. He also asked us to separate his tableware...He said he was sinful and he had done many wrongdoings to our family and community since he became a ‘Si Hao Ke’.” (Respondent, the father of Mr.1)

Mr.13 also thinks he must protect his family and peers from HIV/AIDS in order to make up for his wrongdoings. Thus, apart from the before-mentioned

strategies, he has insisted on using condoms with his wife since he was identified. This information was confirmed by his wife.

2.6.4 The Proud Experience of Being a Peer Educator

In chapter IV, I mentioned there was a HIV/AIDS peer education project going on in the community. This project aims to diffuse basic knowledge and information on HIV/AIDS to villagers through peer educators. The team of peer educators is made up of PLHA and spouses of drug abusers so many of my informants have participated in this project as peer educators. Both they and their families are very proud of being able to contribute to the project. When they shared their experiences of being peer educators with me, they were always excited and proud. They were glad to do something for people and the community in order to atone for what they have done.

Mr.12 is one of the peer educators. One day, I saw him crying while telling his own experiences on HIV/AIDS to villagers. He told me “I like this job. I want to tell people how terrible ‘Si Hao’ is through my own story. I hope there is no new comer to the ‘Si Hao Ke’ group.”

When I visited Mr.1’s family, his father could not help showing me his peer educator certificate and told me: “he has not been able to work for a long time but he was willing to volunteer for the HIV/AIDS education program. He hopes that the young generation will not follow the same disastrous road as him. He also would like to make up for his behavior.”

To confirm my feelings and observation, I spoke with Dr. Li, the coordinator of this project. She told me: “Yes, they are very glad to be peer educators. I have offended one of my relatives by not selecting his son as a peer educator. She has blamed me several times and even she denied our family relationship. I have no idea why they want to do this job. Maybe, they want to make up for their wrongdoings.”

2.6.5 Heroin Reduces the Pain: Health Seeking Behavior

As we know, most drug abusers with HIV/AIDS give up seeking specific treatment for HIV/AIDS but they can access primary health care in the township health center. I was still surprised with what Mr.25 told me. It sounds like “Si Hao” has a double function for drug abusers with HIV/AIDS: satisfying the desire for the drug, and solving health problems.

“I can not abstain from using ‘Si Hao’, I can not recover from HIV/AIDS, I do not have any money and I am prepared for death. When I feel something is wrong with body, I take a little ‘Si Hao’ as medication.” (Mr. 25, a 51-year-old)

CHAPTER VII

CONCLUSION, DISCUSSION AND RECOMMENDATION

1. Conclusion

HIV/AIDS as a current focus of the world is increasing rapidly in China too, especially in the frontier regions where HIV/AIDS was initially found in and spread quickly among the intravenous drug users (IDUs). The Dai people, one of the ethnic groups living along the frontier regions of Yunnan, China, similarly did not escape the corrosion of heroin abuse, so it is no wonder the prevalence of HIV/AIDS is getting more serious among the Dai people. To better understand the issue of HIV/AIDS in the Dai community, the lives of people living with HIV/AIDS (PLHA) have been studied through socio-cultural contexts by exploring the forms and extent of the stigma and discrimination related to HIV/AIDS as well as influencing factors.

Based on a three month ethnographic study in the chosen Dai community, it is clear that we can not understand the lives of PLHA without understanding the lives of drug abusers because 98.5% of PLHA are drug abusers that have been stigmatized and discriminated against since they used heroin.

In terms of opiates, the slang--“Si Hao” meaning “No. 4” has been used to refer to heroin in the community so “Si Hao Ke” (No. 4 person) has become the nickname for drug abusers. To understand the lives of the “Si Hao Ke” in the Dai community, the reasons for being a “Si Hao Ke” and their lifestyles was necessary to examine

several settings including the community, the family and the individual, even after death:---the funeral arrangements in relation to socio-cultural context. A wide range of different forms of stigmatization, discrimination and denial towards the “Si Hao Ke” were identified and the socio-cultural factors were explored, which not only contributed to the original use of heroin but also influences the perceptions, judgments, and responses of people.

The special geographic characteristics of the community create an advantage for the accessibility of heroin. Under peer pressure, curiosity or underrating the effects of heroin, have caused the young generation to follow drug-taking friends into “Si Hao” abuse. Moreover, as a traditional treatment, opium has been used to cure diseases, but some people have come to rely on it after a long-term therapy. Heroin has taken over the position of opium due to its cheaper price and accessibility. However, gender roles place women in a particular position in the Dai family (being too busy with field work and house work, taking care of the whole family), which may keep women away from heroin use.

While sharing common social norms, values, cultural beliefs and practices, the Dai people consider the community as one big family which should be respected, maintained and protected by all the community members. However, “Si Hao” has become an obstacle that isolates the “Si Hao Ke” from this “family” society, since they struggle to get money for heroin, which drives them into immoral practices such as stealing, cheating and trafficking drugs. Such immoral behaviors break the “family” system, so drug abusers are not only punished with written and unwritten social regulations but also rejected from “normal” life.

Within the workplace, the widespread denial that drug abusers are “abnormal” means the majority of employers make unequal treatment and policies on drug-taking

employees. In daily communication, and social activities even after death, the label of being a deviant social group forms the obvious distinction between drug abusers and non-drug abusers. A lack of the communication with “normal” people, and the lack of the equal treatment in daily life force drug abusers to seek equality and a sense of belonging with drug friends, which induce the failure to abstain from drug use and consolidate the stigmatized social status. Nevertheless, the reflections of drug abusers do not criticize the judgments of people, namely that most of them take the understandable opinion that the responses of people in general on account of them sharing the same moral concept of “wrongdoing”—drug abuse.

In the community with cultural systems that place emphasis on leniency, the behavior of drug abusers and their associated behaviors are perceived as the result of personal irresponsibility, and thus individuals are blamed for wrongdoing but their family members should be forgiven and treated equally. However, it is undeniable that drug abuse, unlike other individual behavior, often results in the collapse of the family. Many family members have become impoverished as a result of drug abuse: families have lost their property; parents have lost their material and mental attachments to offspring; women have lost their husbands; children have lost their parents, love, education and guidance. The disappointment and suffering of family members has produced a barrier to maintain the “normal” relationships and contact with drug abusers.

Repentant but being controlled by heroin either physically or psychologically, regretful but being isolated from society, these conditions wear away at the hopes of drug abusers. To cope with the desperation, some drug abusers keep using heroin as an antidote, some pin their hopes on the next life, some give up health care, even life to end the pain.

HIV/AIDS seems to be a new disease occurring and getting more serious among the “Si Hao Ke”, so many “Si Hao Ke” carry a double identities: drug abusers and HIV-positive. In the community, HIV/AIDS is given the meaning of a junkies’ disease, which implies that the “Si Hao Ke” are the suspected population of HIV/AIDS carriers and they should swallow any bitter fruit for using “Si Hao”. Moreover, a clear gradient from “deserved” to “innocent” has formed the discourse surrounding HIV/AIDS. Drug abusers who contract HIV are classified as a most deserved result, whereas, common wisdom suggests monogamous wives infected by their drug-taking husbands are “innocent”.

Even though some PLHA with serious skin symptoms suffer more repulsion, as the collected data shows being a PLHA, this second identity does not reinforce the stigma and discrimination toward drug abusers. In other words, the lives of the “Si Hao Ke” are not changed or further stigmatized owing to HIV infection. On the contrary, in the phase of AIDS, those PLHA receive great health care from relatives, family members and doctors because HIV/AIDS is perceived as less fearful than drug abuse, also because of a consciousness of the need to be kind to any patient, and the mutual assistance system should be maintained among the relatives. Under these positive conditions, internalized responses to HIV/AIDS are also likely to be positive. Most people are willing to disclose their HIV status, to avoid spreading the virus, and to contribute to their relief for the sin.

In conclusion, we must also note that the stigmatization may be developed or reinforced by authorities and outsiders. HIV/AIDS prevention and control strategies should try to alleviate the stigmatization by taking into account pre-existing prejudices toward high risk groups which should not be reinforced by the mass medium or health education. Furthermore, socio-cultural contexts, and the local meaning of HIV/AIDS may be used to re-design more effective HIV/AIDS prevention programs.

2. Discussion

It is obvious either in the literature review or my study that the stigma and discrimination associated with HIV/AIDS are not something that simply springs from the minds of individuals, or occur randomly. They can manifest in a variety of different ways within the diverse socio-cultural contexts. They are linked to many underlying factors either internal or external. The community is often as a whole, playing a key role in producing and reproducing relations of discrimination and nondiscrimination. Here, I would like to discuss some of the points of view around HIV/AIDS stigmas and discrimination which significantly or particularly arise from my case study.

2.1 Pre-existing Local Cultural Prejudices and Practices toward Drug Abusers

In my literature review, I have showed that the stigmas and discrimination in relation to HIV/AIDS do not appear suddenly, and they usually build upon or cooperate with pre-existing stigmatization: about sexuality, about gender, about social class and about race, which was called the double stigma and discrimination by some researchers (Peter M. Nardi, 1990). However, in my study, I think the stigma and discrimination in relation to HIV/AIDS is located under the pre-existing local cultural prejudices and practices toward drug abusers. The stigma and discrimination related to HIV/AIDS may not be the essential reasons causing the “abnormal” life of PLHA, indeed the sticking point is who or which group catches HIV/AIDS. I have compared the lives of drug abusers before being infected with after being infected, and compared the lives of seropositive drug abusers with seronegative drug abusers, and also compared their lives with general population. Whatever can be said, the HIV-positive status does not change their lives markedly, and the stigma, denial or isolation related

to drug abuse are rooted in their lives.

Drug abuse causes several relevant actions such as stealing and cheating which often offend the well-balance of social norms or ruin the peace of families or affect the security of the whole community. Hence, drug abusers are pushed aside by people, and condemned by family members even cursed after death. In contrast, the emergence of HIV/AIDS does not bring as much trouble to the community and families as drug abuse. Although being infected with HIV means facing its incurability and death, drug abusers often die from overdoses, suicide and the long-term effects of heroin, such as collapsed veins, infections of the heart lining, or pulmonary complications. Moreover, on account of the inability to stop heroin use, death seems a better way of disengaging from the drug for families and drug abusers themselves. Thus people are not afraid of HIV/AIDS as much as being drug abuser, nor does it radically impact drug abusers' lifestyles.

Pre-existing local cultural practices and prejudices frequently establish categories of person or types of behavior that are likely to be stigmatized. The advent of HIV/AIDS among drug abusers not only affects the interpretation of people of HIV/AIDS but also frequently reinforces these already existing types of stigma, imbuing them with new and potent legitimacy. In my study, most PLHA are also drug abusers, so people think HIV/AIDS is one of harms of heroin use, which undoubtedly reinforces people's beliefs that drug abuse is evil. In spite of the fact that people know the other transmission patterns of HIV/AIDS, they ascribe HIV/AIDS to drug abusers: drug abusers bring the HIV/AIDS to the community and HIV/AIDS is their deserved retribution, even measures of "guilt" and "innocence" differ between drug abusers with HIV/AIDS and wives with HIV/AIDS. Hence, through the interpretation of slang, HIV/AIDS is a junkies' diseases. Abstention of heroin use and avoidance of physical contact with drug abusers has become an effective prevention strategy for HIV/AIDS.

Definitely, we can not deny that IDUs are more likely to catch HIV/AIDS because they often take high-risk behavior: sharing needles. However, this deduction does not say HIV/AIDS is a junkies' disease, and it is the result of drug abuse.

In addition, these pre-existing prejudices, denial and practices also influence the health seeking behavior of marginalized groups. Drug abusers are isolated from mainstream society, and they also feel guilt themselves. Loneliness, desperation and the stigmatization deprive them of their courage to live, for health, even to seek health care. As a result, being HIV-positive or not, and getting health care or not, are not important any more.

As a matter of fact, drug abuse is not simply a personal behavior, instead, it is an immoral behavior which is a common social problem that can not be solved by condemning the people concerned, and can not be solved unless we work together. Ideally, the long-held ideologies and prejudices surrounding marginalized groups can be removed, and maybe HIV/AIDS will be reinterpreted and PLHA will be judged fairly.

2.2 Knowledge and Stigma

As previous studies show, a lack of knowledge and information on HIV/AIDS, and a misunderstanding of transmission routes combined with the fear of death evoke dread in people towards HIV/AIDS, and stigmas and discrimination toward people living with HIV/AIDS. For example, one study identified that People recognize the role of limited knowledge in perpetuating stigmas and these people are eager to acquire a more detailed knowledge on HIV and AIDS (Laura Nyblade, etc, 2003). However, the impact of lack of knowledge about HIV/AIDS to stigma and discrimination is showing another perspective in my study. I described in chapter VI

that most respondents just knew basic information on HIV/AIDS, and lack a detailed knowledge such as the symptoms, complications and prognosis. Indeed, they perceive HIV/AIDS is a new disease appearing among drug abusers. Even though they adopt strategies to prevent infection, they do not show very much fear and repulsion. On the contrary, they take care of patients until they die. In allusion to this situation, I think a lack of in-depth knowledge on HIV/AIDS may be one of the reasons that people show less fear and repulsion because people do not really understand HIV/AIDS and are not aware of the severity of the disease.

Certainly, I am not saying that a lack of knowledge is an advantage to reduce the stigmas and discrimination. A lack of knowledge is definitely a stumbling block for HIV/AIDS prevention and control. But we should realize that an absence of biomedical knowledge or information is not the determiner for stigma and discrimination associated to HIV/AIDS, and how people perceive HIV/AIDS is much more important. In the community, people regard HIV/AIDS as a junkies' disease and needle sharing is believed to be the most serious pattern of transmission. This understanding may cause both positive and negative responses of people. For example, on the positive side, people show their sympathy to the wife who got HIV/AIDS from her drug-taking husband, and people show their kindness to patient because of less fear of being infected. On the negative side, drug abusers were blamed by people for bringing HIV/AIDS to the community and bringing HIV/AIDS to their wives.

Such faulty understanding may be related to the diffusion of knowledge, the content of information and also influenced by local socio-cultural beliefs. In public campaigns on HIV/AIDS, without being aware, we often overemphasize the negative impacts of HIV/AIDS, the severity of the disease and the prevailing situation, even over-emphasizing the vulnerability of risk groups. As a result, people reflect the information in their bias perceptions. Therefore, how to diffuse the appropriate

knowledge and information, how to develop the proper Information Education Communication (IEC) materials based on local socio-cultural contexts, how to avoid overemphasis of the negative impacts of HIV/AIDS and risk groups are challenges for HIV/AIDS health education programs.

2.3 Religion: A Remarkable Power

Religion has always been part of the social lives of people. It powerfully affects the ideology of people and confines people's behavior. It provides intense moral guidelines for life, for birth, for illness, for death and for interpreting natural events including disasters and misfortune. HIV/AIDS as a new but serious problem is challenging religion which has stood in our society for several centuries.

Many studies show that religion affects the responses of people to HIV/AIDS or PLHA (Jessica Bijdendijk, 1996, Virginia Bond, Elaine Chase, 2002). In my study, we can not see the direct link between Buddhism and HIV/AIDS, but religion influences people's thoughts and practices. For example, based on the doctrine of Buddhism, people believe in metempsychosis of life. Therefore, when family members are disappointed by drug abusers, and when drug abusers despair of life, they pin their hopes on the next life. Likewise, death does not mean only termination but also means the beginning of a new life, the beginning of new hopes. HIV/AIDS is an incurable disease, but the fear of death may play down the fear of HIV/AIDS. Moreover, comeuppance has also been mentioned in Buddhism. The merits and virtues of people collected in this life determine the quality of life in the next life, so people try to present their goodness and kindness to others, especially to someone who needs help. In reflection, most family members and neighbors are now at the frontlines providing care and support for PLHA, particularly for those who are very ill and who are dying. And for PHLA themselves, because of the fear of accumulating sins in this life, they

avoid transmitting the HIV virus to other people.

Sometimes, the stigma related to HIV/AIDS shaped by religion can be powerful. Drug abusers are seen as sinners who deserve to become infected according to the primordial religion. This ideology not only confirms the misunderstanding of people about HIV/AIDS---a junkies' disease, but also reinforces the stigmas and discrimination toward drug abusers.

In conclusion, religion plays an intensive role in people's minds and lives. It is suggested that the perceptions and responses of people toward certain things or certain people cannot be easily changed unless we deal with people's religious beliefs and practices. Hence, HIV/AIDS intervention programs should cooperate with religion, using religious power for HIV/AIDS prevention and control. Religions have their own integral system and abundant resources that can be used for HIV work. Religious beliefs and practices can play roles in the care and support of people with HIV. Religious activities are maintained in people's daily lives. The words and actions of religious leaders are more effective on the people.

2.4 “Normal” and “Special”: the Role of HIV/AIDS Program

First of all, it should be acknowledged that all the HIV/AIDS campaigns implemented in the community including HIV tests, surveillances and health education programs, particularly the peer education program, have contributed much to HIV/AIDS prevention and control. With the progress of these campaigns, people have received relevant knowledge and information on HIV/AIDS, knowing transmission patterns and being aware of prevention. The perception and responses of health professionals toward PLHA have also been changed by attaching themselves to

HIV/AIDS campaigns. Moreover, by taking part in the HIV/AIDS prevention programs, drug abusers and their spouses are able to increase their self-esteem.

However, it is worthwhile to note that many drug abusers with HIV/AIDS and their spouses have mentioned the feeling of being “special” which is rendered by and developed by “outsiders”, “strangers” and “others”. HIV/AIDS policies and programs, even the local authorities, may inadvertently contribute to the overemphasis of the relationship between drug abusers and high-risk behavior, which is believed to reinforce the association of HIV/AIDS with “special groups”. Consequently, the misunderstanding of a junkies’ diseases, and the feelings of being “special” even the stigmatization and discrimination, are incorporated and reinforced the difference between the “general population” and the “special population”, prioritizing actions to prevent HIV being spread to the former from the latter.

Actually, drug abusers have been isolated and denied by mainstream society. Recovering a “normal” life as part of the general population is much more useful and important than special attention. When I interviewed some respondents, I had to ask myself: “shall I continue? Shall I repeat the questions as other people did?” Because they or their family members have already accepted “outsiders” visiting them several times including researchers, program managers, donors and health professionals. They have to share their suffering, their private stories with “strangers” again and again while receiving special or suspicious looks and gossip from neighbors or others.

I have visited a village which developed a care and support project for PLHA. By providing living conditions, jobs and health care to PLHA, they live and work together accompanying general villagers. This is a successful project. However, PLHA have to accept visits and interviews continually from “outsiders” and “strangers” in the project

office where this “special” population will be noticed. I do not dare to say this is a “normal” life, like the general population, even like someone with another disease.

2.5 Symptoms, Grading the Stigma and Discrimination

Before performing this study, I never had any idea that the extent of the stigmas and repulsion could be graded by the symptoms displayed. Namely, people may take further negative responses to people who have certain symptoms. As my data shows, the PLHA who show the symptoms on the skin receive more repulsion and avoidance from people. We should also note such situations may result from the misunderstanding of HIV/AIDS. As the disease progresses, people develop other conditions related to AIDS such as severe shingles, sores or pustules but these are not defined complications for every patient. People regard skin illnesses as typical symptoms of HIV patients, which are more likely to spread the virus to others. In addition, dirtiness and shabbiness are reasons for people to dislike drug abusers, so skin symptoms and their appearance may cause nauseous feelings in people.

Whatever reasons cause people to have negative responses to the PLHA with skin diseases, it is suggested that we should be aware of extent of the stigma and discrimination among people with different symptoms displayed by HIV/AIDS. The proper information on the symptoms of HIV infection should be diffused among people, and health providers should pay more care and apply special treatment to those patients who have easily identified symptoms in order to lighten their suffering.

3. Recommendations

3.1 Reduce the Impact of Pre-existing Prejudices on the Stigmas Related to HIV/AIDS

As discussed early, the pre-existing prejudices and practices on marginalized groups influence people's perceptions and responses toward PLHA and the advent of HIV/AIDS has reinforced these prejudices on marginalized groups. On the one hand, to reduce the stigmas and discrimination in relation to HIV/AIDS effectively, we must consider reducing the pre-existing prejudices on marginalized groups. Nevertheless, the reduction of pre-existing prejudices is not a simple affair, which may need the mobilization and power of the whole community or society.

At least, we should take two sides into account: the social environment and the empowerment of marginalized population. To create a climate in which prejudices are no longer tolerated, first of all, this requires the support of local authorities. The community leaders should acknowledge that some problems such as drug abuse are common social problems rather than individual wrongdoing. Some policies should be developed to protect the rights of drug abusers in the community, workplace, school, health care institution, etc. Media campaigns may address this issue, focusing on their experience of community mobilization and social transformation. In addition, we also need to pay attention to the behavioral change of drug abusers. On account of denial and social isolation from the general population, most of them have lost the confidence to live and socialize. Drugs were sometimes regarded as a pain killer taken by drug abusers. A lack of communication with people in general, a lack of jobs and support from society push them further and further from "normal" life. Thus, they should be encouraged and empowered, not only by improving the quality of treatment they receive, but also by providing information, health care, living conditions and social

support.

On the other hand, to avoid reinforcing prejudices on marginalized people, HIV/AIDS prevention campaigns should aim to move from focusing on certain groups to people in general. The distribution of HIV/AIDS knowledge should avoid over-emphasizing the relationship between HIV/AIDS and high-risk groups.

3.2 Use “Insiders” instead of “Outsiders” in HIV/AIDS Program

The findings show that the long-term intervention of “outsiders” in HIV/AIDS program may arouse or reinforce the “special” feeling of PLHA or marginalized people. In fact, the focus of HIV/AIDS intervention activities should move from high-risk groups to people in general to correct popular myths, stereotypes and judgments regarding HIV/AIDS and reduce the stigmas and discrimination toward high-risk groups.

However, sometimes, it is inevitable that we have to work with high-risk groups. Under these conditions, besides developing policies to protect and safeguard the patient’s privacy and rights during the HIV/AIDS program, we must consider using “insiders” as program executors instead of “outsiders”.

In my study, many drug abusers and their family members feel “special” because of the intervention of “outsiders”, especially staff from the CDPC whose identity has been stereotyped with HIV/AIDS work. Hence, firstly, we can use local health professionals instead of staff from the CDPC to provide services because they work for all community members, reducing the sensitivity of HIV/AIDS to drug abusers. Secondly, an inside network among the drug abusers and family members can be built. Peers can be organized into an assistance group to provide support, and

encouragement to each other. Some key people can first be trained to share the knowledge, policies and prevention strategies on HIV/AIDS within this network without “outsiders”.

3.3 Develop Non-stigmatizing HIV/AIDS Health Education Programs

It was found that a proper understanding and knowledge of HIV/AIDS has important effects on the experience of the stigmas. Thus, it is necessary to develop health education with a consideration for non-stigmatizing information or knowledge.

Health education is a useful intervention tool by virtue of its capacity to diffuse knowledge on health and illnesses, but people may modify and interpret the received knowledge in terms of pre-held prejudices and beliefs regarding health and diseases. Therefore, first of all, assessing current knowledge, beliefs and perceptions on HIV/AIDS that people have may be the first step towards being able to develop proper education materials. Based on this assessment, the language and information used in health education can be modified to ensure that it does not portray HIV/AIDS and PLHA in negative, stereotypical ways; incomprehensible information on HIV/AIDS can be incomplete; and reinforce misconceptions that could be corrected and avoided.

In addition, health education must involve the whole community rather than focusing on certain groups and educators should integrate both high-risk populations and people in general.

3.4 A Faith-based HIV/AIDS Program: Take the Advantage of Religion with HIV/AIDS Programs

As discussed before, religion plays a dominate role in our society, which strongly

influences people's opinions and actions. We can take advantage of religion to address and reduce the stigmas through religious activities alone, or by integrating religious power into other HIV/AIDS programs.

Both religious leaders and activities can contribute to the reduction of the stigmas and discrimination: the knowledge and information on HIV/AIDS can be combined, and modified in religious sermons, making sure that it is non-stigmatizing and non-discriminatory; religious authorities can be used as promoters or demonstrators of care and support for PLHA; religious leaders or monks can be advocated to provide emotional and spiritual support for PLHA; positive religious doctrine such as "kindness" can be used to encourage people to support PLHA.

3.5 Take Advantage of Pre-existing Positive Foundations to Build a Stigma-reduction Program

It is clear that the stigmas and discrimination related to HIV/AIDS can be manifested in a variety of forms, at a variety of levels and in a variety of socio-cultural contexts. We have limited experiences to reduce the stigmas by conducting stand-alone intervention. As findings show, it is believed that there are several positive and strong foundations in society or the community that may benefit stigma reduction. For example, in the community, family members are willing to take care of PLHA. Health professionals providing health care should help reduce the stigmas and discrimination. Therefore, stigma-reduction intervention or activities can build on such pre-existing positive foundations.

3.6 Recommendations for Further Researches

- Comparative research on stigma and discrimination in relation to HIV/AIDS

among other Dai communities: my study was conducted in a remote and poor Dai community which is underdeveloped, and less influenced by the modern society. In addition, almost all the HIV-positive cases result from sharing needles so my study can not exactly represent other Dai communities where the socio-economic background and the situation of HIV/AIDS epidemic are different.

- Research on the responses of other communities toward the community associated with HIV/AIDS: I performed my study within the community so the findings were confined by insider's perspectives. This community is a minority region, where HIV/AIDS prevalence is serious. It will be interesting to identify whether this community or those people who live with HIV/AIDS in this community are stigmatized and discriminated by outsiders from other communities or mainstream Chinese society.

BIBLIOGRAPHY

- Angelo A. Alonzo, Nancy R. Reynolds. *Stigma, HIV/AIDS: An exploration and elaboration of a stigma trajectory*. *Social Sciences & Medicine*, 1995 41(3).
- Blau, Peter M. *The Dynamics of Bureaucracy*. Chicago: University of Chicago Press, 1956 (15) -----, "Structural Effects." *American Sociological Review* 25 (April 1960): 178-93. (2)
- Bruce J. Cohen and Terri L. Orbuch. *Introduction to Sociology—an American Bookworks corporation project*. McGraw-Hill Publishing Company, 1990.
- China faces up to HIV/AIDS epidemic*. *The Lancet*. Vol 362. December 13, 2003. Available from: www.thelancet.com
- Christopher C. Taylor. *AIDS and the Pathogenesis of Metaphor*. Culture and AIDS Edited by Douglas A. Feldman. Praeger Publishers. New York: 1990.
- Discrimination Against People With HIV/AIDS Still an Issue in Australia, <http://www.eldis.org/dbtw-wpd/exec/dbtwpcgi.exe>
- Dooley Worth. *Minority Women and AIDS: Culture, Race and Gender*. Culture and AIDS Edited by Douglas A. Feldman. Praeger Publishers. New York: 1990.
- Douglas A. Feldman. Introduction: *Culture and AIDS*. Culture and AIDS Edited by Douglas A. Feldman. Praeger Publishers. New York: 1990.
- Dovidio, J. F., Major, B., & Crocker, J. (2000). *Stigma: introduction and overview*. In T. F. Heatherton, R. E. Neck, M. R. Hebl, & J. G. Hull (Eds.), *The social psychology of stigma* (pp. 1–28). Guilford Press. Cited in Rebecca Puhl, Kelly D. Brownell, 2003. Ways of coping with obesity stigma: review and conceptual analysis. *Eating Behaviors* 4.
- Editorials. *HIV/AIDS stigma: An impediment to public health*. *American Journal of Public Health*. 2002, 92 (3).

- Godfred Paul. *Cultural Context of Caring*. Presented in World Cultural Day, Chiang Rai, Thailand, 1996.
- Herbert Muyinda, J. Seeley. *Social aspects of AIDS-related stigma in rural Uganda*. *Health & Place*. 1997, 3 (3).
- Horizons of population council. *Research Update---stigma and discrimination*. January 2002.
- Huang Huikun. *A Cultural History of the Dai Nationality*. Yunnan Nationality Publishing Company. 1997.
- How is HIV spread (transmitted). Available from: http://www.medicinenet.com/Human_Immunodeficiency_Virus_HIV_AIDS/article.htm. March, 2 2004.
- Jessia Bijdendijk. "A ripe mango has to fall..." Care for people with HIV/AIDS in a Buddhist Centre in Northern Thailand. Thesis for a Masters Degree, University of Amsterdam. 1996.
- Jennifer Boyd Ritsher, Poorni G. Otilingam. Internalized stigma of mental illness: psychometric properties of a new measure. *Psychiatry Research* 121. 2003.
- Joanna Busza. *Literature review: Challenging HIV-related stigma and discrimination in Southeast Asia: Past successes and future priorities*. Horizons of Population Council. 1999.
- Julic Arboleda-Florez. *Considerations on the stigma of mental illness*. *The Candian Journal of Psychiatry* 48 (10). 2003.
- Laura Nyblade, Rohini Pande and Sanyukta Mathur. *Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia*. International Center for Research on Women (ICRW). 2003.
- Maria Esther Irigoyen-Camacho. *Attitudes of a group of Mexico City Residents toward HIV/AIDS in the dental office*. The department of Health Sciences, Methropolitan Autonomous University Xochimilco and Health Services Research Program, Center for Health Research, Portland.

- Martha J. Morrell. *Stigma and Epilepsy*. *Epilepsy & Behavior*. 3 S21-35. 2002.
- Martin N. Marger, 1996. *Race and Ethnic Relations—American and Global Perspectives*. Wadsworth Publishing Company.
- Michael D. Quam. *The sick role, stigma and pollution: the case of AIDS*. *Culture and AIDS* Edited by Douglas A. Feldman. Praeger Publishers. New York: 1990.
- Paul Farmer. *AIDS and Accusation: Haiti, Haitians, and the Geography of Blame*. *Culture and AIDS* Edited by Douglas A. Feldman. Praeger Publishers. New York: 1990.
- Paul Farmer. *AIDS-Talk and the Constitution of Cultural Models*. *Social Sciences and Medicine*. 38 (6). 1994.
- Peter Aggleton. *Comparative Analysis: Research Studies from India and Uganda: HIV/AIDS related Discrimination, Stigmatization and Denial*. UNAIDS, 2000.
- Peter Aggleton and Richard Parker. *HIV/AIDS-related Stigma and Discrimination: A Conceptual Framework and an Agenda for Action*. Horizons of population council, 2002.
- Peter M. Nardi. *AIDS and Obituaries: The Perpetuation of Stigma in the Press*. *Culture and AIDS* Edited by Douglas A. Feldman. Praeger Publishers. New York: 1990.
- Pimpawun Boonmongkon. Khi thut, “The disease of social loathing”: An anthropological study of the stigma of Leprosy in rural North-east, Thailand. *Social and Economic Research Project Reports*. 1994.
- Ria Reis, Harry Meinard. ILAE/WHO “out of the shadows campaign” Stigma: does the flag identify the cargo? *Epilepsy & Behavior*. 3, 2002.
- Robert H. Lauer, Warren H. Handel. Chapter 6-the process of creating deviants. *Social Psychology: The theory and application of symbolic interactionism*. Houghto Mifflim Company. Boston,1977.
- Rose Weitz. *Life with AIDS*. Rutgers University Press: New Brunswick, New Jersey, 1992.
- Roy Porter. *Can the stigma of mental illness be changed?* *Stigma of mental illness*.

The Lancet. 1998 (352).

UNAIDS. *Report on the global HIV/AIDS epidemic*, 2000.

UNAIDSa. *Fact sheet, stigma and discrimination*, 2003. Available from:
<http://www.unaids.org>

UNAIDSb. *Vulnerable population*, April 2003. Available from: <http://www.unaids.org>

UNAIDSb. *Care and support*, April 2003. Available from: <http://www.unaids.org>

UNAIDS and WHO. *AIDS epidemic update*, Dec, 2003.

Vera Paiva, Elvira Ventura, 2003. *The right to love: the desire for parenthood among men living with HIV*. *Reproductive Health Matters* 2003. 1(22).

Virginia Bond, Elaine Chase. *Stigma, HIV/AIDS and prevention of mother-to-child transmission in Zambia*. *Evaluation and Program Planning* 2002 (25).

APPENDIX

APPENDIX

Interview Guideline

(PLHA and family members)

After gaining the trust of people, researcher should introduce herself first and explain the purpose of interview and the importance of this study. The researcher also should try to create a light-hearted environment for interviewees. This guideline was taken as a basic guidance to conduct in-depth interviews to PLHA and their family members. The questions could be changed and added depend on real situation and the differences of cases. Informal conversations and observations were applied to obtain and complete information.

Social background of the respondents

1. What are the social-demographic characteristics of the respondents in terms of age, ethnicity, marriage status, occupation, social status, economic status, roles in the community?

History of being a “Si Hao ke”

1. How did they become a “Si Hao Ke”? What time? Why?
2. How do they share “Si Hao” with drug-taking friends? Why?
3. How do they live in the community after being a “Si Hao Ke”? And why?

How do they spend their daily lives? How do they afford “Si Hao”? How do they communicate, work and share lives with people in general? How do community members treat them? How do they react to people? Is there any special punishment

for them?

4. How do they live with family members?

What are their feelings? How do family members treat them? How do they react to family members?

5. How do they perceive their behavior and identity? And why?

6. How do family members live in community?

Background of being PLHA

1. What are their histories of being infected with HIV/AIDS?

When was the first time they knew their infections? How did they know? How did they get HIV/AIDS? (Sharing needles, from partner [Sexual contact], from mother...)

2. How were their HIV-positive status disclosed?

When did their family members know their status? When did their neighbors or community members know? How did they know?

3. What about their health now?

How are the symptoms displayed? When do symptoms occur? Where and how can they get treatment?

Perceptions of HIV/AIDS:

1. How do they know and think about HIV/AIDS in terms of symptoms, transmission routes, prevention strategies, and prognosis?

2. Is there anything about HIV/AIDS they do not know? Why?

3. How do they call HIV/AIDS in the Dai community? What are the meanings? Why?

Experience of being a PLHA:

1. What are their feelings of being a PLHA in the Dai community?

How do they feel after being a PLHA? Why? (Fear, lonely, shameful, sinful, self-stigmatization, worthlessness, lack of self-esteem...) How do their family members feel? How do community members feel? Is there difference among different stages of being infected with HIV?

2. What are their experiences of living with HIV/AIDS in the Dai community?

Can they still live in the community? How do other people treat them in the workplace, religious place, and other social institutions? Is there any difference between before and after being infected?

3. How do they live with family members?

Have they been rejected? How do family members treat them? Why?

4. What are their responses to HIV/AIDS? And why?

Do they blame and stigmatize themselves? Do they give up seeking care and treatment? Do they isolate themselves from community or family? Have they hid their status to others? Do they use condoms when they have sex? Do they still share needles with other drug users?

5. How do family members live in community?

Interview Guideline

(Key informants)

This interview guideline was developed for the key informants. Before conducting interview, interviewer should introduce herself and explain the purpose of interview. Four parts compose this interview guideline. The first part is social background of the key informants. The second part is social and cultural background of the Dai people. Researcher tries to start to ask the questions related to the history of the Dai community, and common diseases in the Dai community. It aims to create easy atmosphere, to get basic information of the Dai people and to compare the differences and similarities between HIV/AIDS and other diseases. Perceptions and situation of HIV/AIDS epidemic in the Dai community make up of the third part. In the fourth part, the questions focus on responses of the Dai people to HIV/AIDS. Some specific questions was selected or added based on real situation and different respondents.

Social background of the Key informants

1. What are the socio-demographic characteristics of the key informants in terms of age, gender, occupation, social status, economic status, education and roles in the community?

Histories and social contexts of the Dai community

1. Where is the study community? How far is it from the nearest county/town?
2. How old is it? When was it established? By whom?
3. What are the major developments of the community? Is it changed with the developments? What is the common way they make for living? How much the income for one family per year?

4. How is the community structure? How many community members in this community? Where are they from? How many ethnicities in this community? And what are they? How many households in this community? How many surnames Dai people have in this community? And what are they?
5. How is the common family structure? How many people live together in each family? Who are them?
6. Who are the community leaders? How do they fulfill their duties?
7. How about the relationships among the Dai people in terms of social status, age, gender, economic status and bloodline? How do they fulfill their roles? How do they communicate each other?
8. How do community members communicate with outsiders? How do they access information? How do they get transportations?
9. How do Dai people spend their time?
10. What is the dominant religion in the Dai community? Who are the religious leaders? How are their duties and statuses? How do Dai people practice religious activities?
11. What are the common diseases in the Dai community? How is it? How do people feel it and treat it? How do people think the sick people and treat them?
12. What are the cultural beliefs and norms on birth, death and sexuality? What are the taboos for man and woman in the Dai community? Is there any different perception among different deaths? And how? What are the beliefs, attitudes and practices on sex in the Dai community? How do Dai people perceive drug users and sex workers? And why?

Histories of “Si Hao”

1. What time did “Si Hao” appear in the community? How many people involve in using “Si Hao” and why?
2. How do people think of “Si Hao” and “Si Hao Ke”?

3. How do people cope with “Si Hao” and “Si Hao Ke”?

Perceptions and situation of HIV/AIDS in the Dai community

1. What is the situation of HIV/AIDS epidemic in the Dai community? What time did HIV/AIDS occur in Dai community? How about the tendency of epidemic? What is the major transmission route? What are the characteristics of PLHA? How many people have been infected? How many infected people died? How many orphans in this community?
2. What are the campaigns to cope with HIV/AIDS that the government or NGOs have been done in this community? How is it? Is it useful or useless? Why?
3. What are the government strategies for tests, report, surveillance and service related to HIV/AIDS?
4. Where can people test the HIV? Who should to be tested? Does the government allow everyone know who is HIV-positive? How does the government manage all cases? How does government provide health care for PLHA?
5. How do people understand HIV/AIDS in terms of symptoms, transmission routes, consequences and prevention strategies? Where can people get knowledge and information on HIV/AIDS? How do people use their local language to describe HIV/AIDS?
6. How do Dai people perceive community members with HIV/AIDS? Why? Is there any different perception on different PLHA in terms of age, social status, gender, economic class and age? And why?

Responses to “Si Hao Ke” and PLHA (following questions was asked twice in terms of “Si Hao Ke” and PLHA):

1. How do the Dai people live with drug abusers/PLHA? Do Dai people blame or punish them? Do Dai people deny traditional rituals for them? (e.g. funeral

practices; restricted access to marriage) How do Dai people contact, communicate and work with them?

2. What is the situation of stigma and discrimination in the health center? How do health providers perceive or feel “Si Hao Ke”/PLHA? What are the attitudes of health providers toward them? How do health providers treat them? Is there any different treatment between PLHA and other community members?
3. How do people respond to “Si Hao Ke”/PLHA from religious perspective? Why? How do the Dai people talk about drug abusing/HIV/AIDS in religion? How do the Dai people allow them to participate in religious activities?
4. Is there any difference between “Si Hao Ke” and PLHA? And why?
5. Is there any difference between before being infected and after being infected?

Guideline for observation

The following questions led the researcher to conduct the observations during the period of data collection.

1. How is the community setting?
2. How is the common family structure?
3. What are the daily lives of the Dai people?
4. How do the Dai people communicate each other?
5. How do the Dai people practice traditional or religious rituals in the community?
6. What are the lives of “Si Hao Ke”/PLHA in the Dai community? How do they live with family members? How do they live with community members? How do they communicate with community members? How do they work with others? How do they seek health services? How do they attend social activities? How do their family members live in the Dai community?
7. What are the reactions of the Dai people when they hear or contact PLHA?
8. What are the reactions of respondents during in-depth interviews or conversations? (expression, body language)

GLOSSARY

Slang term used among community members in Chinese or the Dai language	Translation	Real meaning
Si Hao	No. 4	Heroin
Si Hao Ke	No. 4 person	Drug abuser
Yi Hao	No. 1	Opium
Er Hao	No. 2	morphine
San Hao	No. 3	Bhang
Mang	Natural village	Natural village
Zhai Zi	Natural village	Natural village
Xing Zheng Cun	Administrative village	Administrative village
Xi Zhai Zi	Washing village	A sacrifice to the community
Bai		Devotional obligation
Zhuang Fang	Buddhist temple	Buddhist temple
Xiao Miao	Small temple	Traditional altars
Hao Ren	Good person	Non-drug user
Si Xiao Jie	No. 4 beauty	Heroin
Chi	Eat	Snorting and smoking heroin
Da Zhen	Injection	Injecting heroin
A La Xi Ya	Junkies' disease	HIV/AIDS
A La Bing Dong	Junkies' impetigo	HIV/AIDS
Yan Dan Bing	Patient	If this word was used by drug abusers, it means PLHA
Hai Gun	A person who sell their arse	Sex worker

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