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"I Didn't Feel Like Living": The Prevalence, Perceptions, and Prevention of HIV/AIDS Among Tibetan Refugees in Kathmandu

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The evil that is in the world almost always comes of ignorance, and good intentions may do as much harm as malevolence if they lack understanding.

Albert Camus, *The Plague*

Abstract

The fight against HIV/AIDS is a global one, a concern that is addressed by both the Nepali government and the Tibetan government in exile. Both governments have taken measures to prevent the further spread of the epidemic among their populations, increase knowledge and awareness about the disease, and provide better treatment and care to those living with HIV/AIDS. However, there is a gap between these efforts, particularly within the Tibetan refugee community. As a result of Tibetan's refugee status in Nepal, fewer resources have been allocated for dealing with and understanding the risk factors for Tibetans in exile in Nepal. Without a commitment by the Nepali government, international health care organizations, or the Tibetan government in exile to understand the particular risk factors for Tibetans and their perceptions of HIV/AIDS, any efforts that aim to control the transmission of HIV will be futile.

Using interviews with former Tibetan drug users, Tibetans who are HIV positive, Tibetan doctors and Tibetan government officials, I examine a) HIV risk factors for Tibetans living in Nepal, b) Tibetan perceptions of the prevalence of HIV/AIDS in their community, c) the stigma associated with HIV/AIDS in the Tibetan community and d) additional risk factors that make Tibetans especially vulnerable to the transmission of HIV/AIDS.

I conclude by offering recommendations for further research that seek to improve the structural and environmental context in which awareness and prevention programs aimed at Tibetans in Nepal are implemented. The very fact that HIV/AIDS is a largely undocumented topic among Tibetans in Nepal suggests that research on this issue should be pursued. However, such research must be executed with awareness of the cultural and political context that it is working under. More focused attention on how Tibetans actually behave and perceive their risks for HIV transmission is a critical tool in combating the spread of the HIV/AIDS.

Acknowledgments

I would like to offer my most sincere gratitude to those that were courageous enough to talk with me but wish to remain anonymous. I greatly appreciate their willingness to share very personal and difficult accounts of what their life is like living with HIV as a Tibetan in exile in Nepal. Their accounts acted as foundation for this paper and have deeply inspired me.I would also like to express deep gratitude to Kunsang Lama, who provided me with multiple interviewees, guidance, and support. I would not have been able to develop an understanding of HIV/AIDS among the Tibetans in Kathmandu without his help. Finally, I wish to express my sincere appreciation to all of those who graciously met with me and shared their understanding of HIV/AIDS among Tibetans in Nepal.

Acronyms

AIDS	Acquired Immunodeficiency Syndrome
CHBC	Community and Home Based Care
CHOICE	A Dharamsala based HIV/AIDS Initiative, established in 2007
CTA	Central Tibetan Administration
DOH	Department of Health
FSW	Female Sex Worker
HIV	Human Immunodeficiency Virus
IDU	Intravenous Drug User
LGBT	Lesbian, Gay, Bisexual, Transgender
MSM	Men who have Sex with Men
MSW	Male Sex Worker
NCASC	National Center for AIDS and STD Control
NGO	Non-Governmental Organization
PLHA	People Living with HIV/AIDS
SPARSHA	Society for Positive Atmosphere and Related Support to HIV/AIDS
UNAIDS	Joint United Nations Program on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS

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Introduction: "Not Many Tibetans Have HIV"

"When I found out, I didn't feel like living." Although we had only known each other for a short hour, this is did not hinder Tashi Lama's willingness to share with me her history of drug abuse, nor did it stop her from telling me that she was HIV positive, something she has only shared with her father and boyfriend.[1] Tashi is twenty-six years old, although she looks to be much younger. A soft-faced woman with thick black hair, she now lives amongst other recovering drug users in a female drug rehabilitation center in Patan. Tashi began using intravenous drugs nine years ago, after finishing the twelfth grade; she was only seventeen. Like many other stories, Tashi was not interested in drugs at first, but when her friends began injecting drugs, she decided to try it as well. Six months ago, Tashi discovered that she was HIV positive.

"I was surprised. Not many Tibetans have HIV. It is not a big issue." She told me that because she had not heard of other Tibetans that were HIV positive, she assumed that it was most likely not a major phenomenon. I reminded her that she had not told others of her status either and I asked her to consider whether there might be Tibetans similar to her, who fear disclosing their status, who dread being ostracized by their community, and thus live in silence. "Yes, that is possible," Tashi responded.

Economist Amartya Sen described the global AIDS epidemic as one that, like other major human disasters that, "thrives on ignorance."[2] He wrote that "to understand a problem with clarity is already half way to towards solving it."[3] Yet, understanding the problem is complex task, one that "requires a broader and more foundational cognizance of the nature of the

[1] Name has been changed. Anonymous, interview by author, Patan (November 21, 2009).
[2] Amartya Sen in the foreword to *AIDS Sutra* (New Delhi: Random House), p. 1.
[3] Ibid.

affliction that attacks us from its safe haven of dense fog."[4] The knowledge of the AIDS epidemic is often buried beneath layers of societal and cultural stigmas, behavioral norms, and institutional structures that impair the diffusion of relevant information, making it challenging for Tibetans to develop a comprehensive understanding of the disease.

In Nepal, the fight against HIV/AIDS has been both vigorous and creative. I have seen the phrase "No condom…no fuck" etched in permanent marker on a seat in a crowded microbus; I witnessed a man become the "world's fastest kisser," kissing 130 men in under a minute to end discrimination against those living with HIV/AIDS; and I have met with ex-drug users that volunteered to clean the Boudha stupa in order to raise awareness about the risks of HIV/AIDS. The Central Tibetan Administration (CTA) has similarly responded with force to the HIV/AIDS epidemic. To mark World AIDS Day on December 1st, the Department of Health (DOH) along with CHOICE, an organization in Dharamsala working with HIV/AIDS, organized a "Run for AIDS" flagged off by Miss Tibet 2009 and held a drawing competition with HIV/AIDS as the theme. Both the Nepali government and the CTA have taken innovative measures to prevent the spread of the epidemic among their populations, increase knowledge and awareness about the disease, and provide better treatment and care to those living with HIV/AIDS. However, the efforts of the Nepali government and Nepali NGOs and the efforts of the CTA and Tibetan DOH have missed one community: The 20,000 Tibetan refugees in exile in Nepal.

This gap in awareness and prevention programs directed at Tibetans refugees in Nepal has left the prevalence of HIV/AIDS among Tibetans Nepal both undocumented in terms of empirical data, but also un-scrutinized in terms of individual and community perceptions of the disease. AIDS organizations in Nepal work to combat the epidemic among Nepal's high-risk

[4] Amartya Sen in the foreword to *AIDS Sutra* (New Delhi: Random House), p. 1.

population and do not work with nor survey Nepal's refugee community. Although the CTA and the Tibetan DOH have taken preventative measures against HIV/AIDS among Tibetans in exile, their efforts have been geared mostly to those living in India, where the majority of Tibetans in exile reside. Their efforts regarding HIV/AIDS among Tibetans in Nepal have been minimal and do not address the complexity of the issue.

As a result of this institutional structure, popular awareness of HIV/AIDS among Tibetans living in Nepal has been severely impeded. Few, like Tashi, think that it is a problem among Tibetans. Yet, it is this logic that exacerbates the problem, reinforces the stigma surrounding the epidemic, and mutes dialogue about the issue. If Tibetans are unable to realize the extent of HIV/AIDS within their own community—to even address HIV/AIDS as a significant problem— they will be hampered in their efforts to address the epidemic.

Perhaps most detrimental to understanding HIV/AIDS among Tibetans in Nepal is that their refugee status has prevented initiatives by the Nepali government, Nepali organizations, and the Tibetan DOH that focus on the fundamental causes within the Tibetan community. What are the primary ways in which Tibetans are contracting HIV and how does their status foster silence? Why does Tashi think that HIV is not widespread and what are the consequences of her ideology? What are the social conditions that limit access to more knowledge about HIV/AIDS and how it is transmitted?

Four weeks ago, I started asking these questions. I was eager to explore the peculiar position of Tibetans in Nepali society and how it affected their interactions with and perceptions of HIV/AIDS. I began by questioning Tibetans that I knew in Boudha about their perceptions of HIV/AIDS in their own community, I visited local health clinics and frequented an HIV hospital in Kathmandu; and I spoke with Tibetan health officials to gain their understanding of the

problem.[5] Slowly, these small leads evolved: I had tea with Sunil, an ex-drug user, where he taught me the street terms for the different qualities of heroin; I offered Tashi cookies while we took a break and gossiped about boyfriends; and I hesitated when Sonam started to cry after I asked her about her dead husband's occupation. I came to know Kathmandu by foot, microbus, bicycle, and taxi as I met with a "friend of a friend who knew someone that was HIV positive," as I questioned Nepali HIV/AIDS support groups and treatment centers, and as I negotiated my way into meetings with those that were uninterested in my endeavor.

At times, these conversations overwhelmed me. They demonstrated how complex the social context of HIV/AIDS is and how individual perceptions of HIV/AIDS are often formed based on little concrete knowledge. I wondered how a handful of private conversations could elucidate a larger issue and point others in the right direction for future research. Yet, despite the current lack of initiatives that aim to gather statistical data or to understand how the Tibetan community actually perceives the issue of HIV/AIDS, the intricacies discovered through my conversations have left me with a surprising degree of optimism. Future initiatives that aim to understand the similarities and differences between Tibetan and Nepalese HIV high-risk behavior, that address the underlying understanding of HIV/AIDS and the risk of HIV contraction, and that act with full cognizance of the social conditions that hinder awareness and prevention efforts have the potential to really help bring to light what has been left in the dark.

[5] Built around the Boudhanath stupa, Boudha is a district in Kathmandu that is home to a large population of Tibetans in exile.

This photograph is of a poster at the Tibetan Reception Center in Swayambhu promoting safe sex. The poster is produced by the Burnet Institute, a group that is conducting behavioral surveillance of groups who are vulnerable to HIV and STI transmission in Lhasa. Despite efforts such as these that address HIV/AIDS in Tibet, there is little that is being done in Nepal to address HIV/AIDS among Tibetans in exile. Even at the Tibetan Reception Center, new arrivals are not tested for HIV.

Drugs, Sex and Migrant Labor

Karma Tenzin took another swig of his murky *chang* in a re-used Coca-Cola plastic bottle as I sipped my tea. Karma, a twenty-eight year old Tibetan man, stopped using drugs nine months ago. He told me that now he "only drinks," raising his *chang* and referring it as a "socially acceptable drug." Drug use is a "big problem in the camp," Karma Tenzin told me, referring to the Jawalkhel Settlement Camp that he was born and raised in. "It is a big problem because it is hard to stop."[6]

Unlike many nations in Africa, where the epidemic is rampant amongst all sections of the population, HIV/AIDS in Nepal is a concentrated epidemic, affecting specific at risk populations. UNAIDS estimates that less than one percent of Nepal's total population is HIV positive.[7] Since 1988, when Nepal saw its fist case of HIV/AIDS, the epidemic has spread

[6] Karma Tenzin, interview by author, Patan (November 19, 2009).
[7] Estimations of people living with HIV/AIDS (PLHA) are 70,000 out of a total population of 28,563,377. UNAIDS, *UNAIDS: Nepal*, 2009, http://www.unaids.org/en/CountryResponses/Countries/nepal.asp (accessed November 15, 2009).

primarily through at risk populations: injecting drug users (IDU), female sex workers (FSW), male sex workers (MSW), men who have sex with men (MSM), and Nepal's large population of migrant laborers. It is typically these groups that engage in high-risk behavior that make them susceptible to HIV contraction. As a result, most HIV/AIDS research institutes and support groups in Nepal focus their work on these populations. Tibetans are not included in any of the numbers recording the prevalence of HIV/AIDS among these populations, yet not being accounted for does not inoculate the Tibetan community from the risks of HIV transmission in Nepal.

"It's a problem here, but it's a problem everywhere," Karma told me, referring to the prevalence of drugs in the camp.[8] Intravenous drug use is one of the most common ways in which HIV is contracted in Nepal and there is no reason to believe that Tibetans are exempt from these patterns. There were 2,521 reported cases to the National Center for AIDS and STD Control (NCASC) of HIV by drug use in 2009, representing 17% of all HIV cases in Nepal.[9] These high numbers have raised the concern of the Nepali government and NGOs working with HIV/AIDS. They have scaled up prevention and awareness efforts addressed specifically at Nepal's IDU population and as result, the prevalence of HIV among IDUs has decreased substantially. In 2005, the Joint United Nations Program on HIV/AIDS (UNAIDS) estimated that more than half of Nepal's IDUs were HIV positive, yet in 2007, this figure dropped to only 34% among all IDUs in Nepal and 21% of IDUs in the Kathmandu valley [10] Dr. Krishna K. Rai,

[8] Karma Tenzin, interview by author, Patan (November 19, 2009).
[9] NCASC, *Cummulative HIV and AIDS Situation of Nepal* , Government of Nepal, Ministry of Health and Population (NCASC, October 2009). Estimates by the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) are larger, suggesting that HIV cases by IDUs represents 34% of all HIV cases in Nepal. UNGASS, *UNGASS Country Progress Report: Nepal* , (UNGASS, January 2008).
[10] HIV Policy ActionAid, *Time to Act: HIV/AIDS in Asia* , (ActionAid, 2005).

director of NCASC, remarked that these numbers are representative of both NGO and national efforts to increase awareness and prevention programs among the most at risk populations in Nepal.[11]

However, none of these efforts are aimed at the Tibetan community, despite that Tibetans face similar risks, hence one reason why drug use is "hard to stop," as Karma explained, is because no one—the CTA, Nepali NGOs, the Nepali government—is trying to stop it. Mr. Dhundop Tsering Lama, the Settlement Officer for the Tibetan community in Boudha, also agreed that drug use was a major problem among the Tibetan youth but recognized that it was an issue that his office was not addressing.[12]

The Tibetan Settlement Office is also not addressing the issue of female and male sex workers, despite that the prevalence of sex work is rampant in Nepal. United Nations General Assembly Special Session on HIV/AIDS (UNGASS) estimates that there are 30,000 female sex workers (FSW) in Nepal, although NGOs estimate this figure to be much higher.[13] Of all the sex workers in Nepal, NCASC reported that there were 836 cases of HIV among FSWs in Nepal in 2009.[14] As of 2007, HIV prevalence among FSWs and their clients was less than two percent and one percent respectively.[15] Tibetan women are not immune to the same factors that drive Nepali women into this work. Tibetan ex-drug users who I met with were adamant that there were many Tibetan women that worked as sex workers in Thamel. Ganden Tashi, a well-established Tibetan in Kathmandu who interviews all new arrivals from Tibet at the Tibetan Reception Center in

[11] Krishna K. Rai, interview by author, Kathmandu (November 26, 2009).
[12] Dhondup Tsering Lama, interview by author, Kathmandu (November 24, 2009).
[13] UNGASS.
[14] NCASC.
[15] USAID, *USAID Nepal: HIV/AIDS Health Profile*, (USAID, 2008).

Swayambhu, was also convinced that Tibetan women work as sex workers in Thamel.[16] Tashi Lama did not think that there were many female sex workers, but admitted that it is a topic that is not talked about at all. "If anyone [in the Tibetan community] found out about her, she would not survive," Tashi explained. "If it exists, no one knows about it."[17] Despite that neither the CTA nor any Nepali organizations work specifically with Tibetan sex workers, there is reason to believe that Tibetan sex workers face similar risks for HIV as Nepali sex workers.

An even larger undiscussed issue, both in Nepali and Tibetan society, is the topic of male sex workers (MSW) and men who have sex with men (MSM). There are no official records of how large the MSM community in Nepal is, largely because in Nepal, as elsewhere in Asia, it is hard to identify MSM as a discrete population.[18] An ethnographic study done by Family Health International (FHI) states that "Male to male sex in Nepal does not exist in isolation. Rather, sex takes place between social and sexual networks and sexual activity patterns that are intimately integrated into the sexual lives of the so-called 'general population,' of which men who have sex with men are themselves, a part."[19] Further, there is no division between men who have sex with men and men who have sex with women. This makes it particularly difficult to target the MSM

[16] Ganden Tashi, interview by author, Kathmandu (November 24, 2009).
[17] Anonymous, interview by author, Patan (November 21, 2009).
[18] The MSM community in Nepal has strongly objected to the term "MSM." They prefer to be referred to as the third gender, as it deconstructs the gender binary enforced in the term MSM. Roger Winder insists that the "term men who have sex with men (MSM) describes a behavioral phenomenon rather than a specific group of people. It is generally the preferred term because, in the context of HIV, the most important issue is *risk behavior* rather than *sexual identity*. It includes not only self-identified gay and bisexual men, but also men who engage in male to male sex and self identity as heterosexual or those whose sexual identity is but a part of their cultural self identification. In some contexts, "males who have sex with males" is more accurate as some programs may target males who are not yet adults." Roger Winder, *HIV and Men Who Have Sex with Men in Asia and Pacific*, (Geneva: UNAIDS, 2006).
[19] Sunil Pant, *Rapid Ethnography of Male to Male Sexuality and Sexual Health*, (Kathmandu: Family Health International, 2001).

population as many of these males do not identify themselves as part of a conventional community and thus, are largely invisible.[20]

Among the Tibetan community, MSM and MSW are also largely invisible. Karma Phuntsok, a twenty-eight year old ex-drug user, adamantly declared, "There is no homosexuality in Tibet."[21] I pushed him further, asking Karma if he really believed that to be true. Karma smiled and brushed off my questions with a smile. Karma's disbelief in the prevalence of homosexuality among Tibetans illustrates how convoluted addressing HIV risk for MSM and MSW is in the Tibetan community. For both Tibetans and Nepalese, in order to address HIV concerns, it is first critical to address the at risk community, a task that is complicated by layers of social and cultural norms.

In contrast to the invisibility of MSM and MSW, migrant work is unconcealed. It is common occurrence in both Tibetan and Nepali families for the husband to travel to India frequently for work. Nepal's 1.5 to 2 million migrant workers account for the majority of Nepal's HIV positive population. According to Nepal's 2007 UNGASS report, labor migrants make up 41% of the total known HIV infections in the country.[22] Short-term, seasonal migration of young men to urban areas of Nepal and India is increasingly common, creating long periods of time in which they are separated from their wives and families. Recent data also shows that 27%

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[20] Complicating the situation further is that bisexual behavior is reported by many MSM and MSW. In a behavioral studies among MSM and MSW in Kathmandu in 2006, 45% of the MSW and 67% of the MSM reported that they had bisexual behavior in the last year. More, 26% of MSW and 42% of MSM reported that they were married. "Review of Existing and Emerging Patterns of Sex Work in Nepal in the Context of HIV/AIDS," A Study on Behalf of Regional Support Team, Asia and the Pacific, UNAIDS (2008).

[21] Karma Phuntsok, interview by author, Patan (November 19, 2009). Despite Karma's ideas, the Blue Diamond Society, Nepal's only LGBT society, informed me via email that they have many Tibetan members. Blue Diamond Society in an email to author (November 22, 2009)

[22] UNGASS

of migrants engage in high-risk sexual behavior when they travel to India.[23] As a result of the high rates of HIV among migrant workers, 21% of people living with HIV/AIDS (PLHA) in Nepal are wives or partners of HIV positive men.[24]

I met with one of these wives, a woman that has become an un-documented statistic because of her refugee status. A friend had agreed to call her for me, a call that I had anticipated to be an introduction, allowing me to set up a time to meet her later on. Yet Sonam agreed to come right away and shortly we sat feet apart from each other.[25] Judging from her willingness to meet with me, I had anticipated someone that was eager to talk, perhaps even excited that someone was interested in her story. Sonam was not this person. She answered my questions with minimal dialogue and rocked awkwardly back and forth in her chair.

Fighting back tears, Sonam told me that her husband died eight years ago from AIDS. She discovered three years ago that she was HIV positive. I learned that her husband traveled to Delhi frequently, working in the sweater business. While I drew the connection quite easily, Sonam claimed to have "no idea" as to how her husband contracted HIV/AIDS.[26] Sonam has two young children, explaining to me how difficult it is to provide for them with no income, although she smiled with relief when she told me that they were both HIV negative.

Unfortunately, I do not think that Sonam's story is unusual. Many Tibetan men, like Sonam's husband, travel to Delhi frequently, selling and buying sweaters and other merchandise to then sell in Kathmandu. Twenty-nine percent of approximately 120,000 Tibetan refugees

[23] UNGASS.
[24] Ibid.
[25] Name has been changed.
[26] Anonymous, interview with author, Kathmandu (November 24, 2009).

living in Nepal and India are engaged in migrant work.[27] Thus, like Nepali migrant workers, Tibetan men are at similar risks for contracting HIV/AIDS from sex workers in Delhi, and thus Tibetan wives are at risk for HIV as well.

Although none of these statistics represent Tibetans in Nepal, behaviors that Nepalese engage in are not foreign to Tibetans. Tibetans that engage in migrant work, sex work, and drug use face similar challenges and risks of HIV as the Nepalese. The similarities in these risk behaviors are compelling and are critical to understanding the complexity of Tibetans' relationship with HIV/AIDS in Nepal.

"No one thinks it is problem"

One important gauge of how populations react and interact with HIV/AIDS is how they perceive the presence of HIV/AIDS within their own community and how individuals perceive their risk of contraction. Tibetan perception of what HIV/AIDS is, how it spreads, and how prevalent it is among their community is critical in developing methods to combat the disease. Unfortunately, understanding individual and community perceptions of the nature of the disease, of its prevalence, and of how individuals perceive their risk of HIV is something that is very challenging to assess.

HIV/AIDS is an unspoken issue among Tibetans in exile, mainly because the behavior associated with HIV/AIDS is taboo. Dr. Rai explained, "No one talks about sex or sex related things, so then how can they speak about HIV?"[28] Even Sonam and Tashi, the two HIV positive women who I met with, did not know anyone else with HIV. "People are scared to tell [their HIV

[27] Patricia Kissinger, Deborah Hoadley Dechen Tsering, "Knowledge and attitudes about HIV/AIDS among health care professionals serving Tibetan refugees in northern India," *International Journal of STD & AIDS*, no. 9 (1998): 58-62.
[28] Krishna K. Rai, interview by author, Kathmandu (November 26, 2009).

status],” Tsering Dorjee told me, a thirty-eight year old ex-drug user. “So no one thinks it is a problem.”[29] Tsering knew no one else with HIV and claimed that it was not something that was talked about.

This kind of logic is particularly detrimental to developing a complete understanding of people’s perception of the disease, and ultimately, most harmful to combating the epidemic. In rural Malawi, a study was conducted that aimed to evaluate the role of “informal conversations in changing behavior and attitudes towards family planning and HIV/AIDS.”[30] Among their findings, they concluded that social interactions about HIV have significant and substantial effects on how people develop perceptions of their risk of HIV.[31] They discovered that the probability of a respondent being very worried about HIV/AIDS increases with the prevalence of HIV/AIDS concern in his/her network.[32] The findings from this survey indicate how critical it is for there to be a high level of concern, followed by discussion about HIV/AIDS in order for individuals’ perceptions of their risk of HIV to be elevated. While the Tibetan community is certainly vastly different than rural Malawi, the study can indicate how inimical the lack of informal conversations about HIV/AIDS can be to controlling the spread of the disease.

The effects of this lack of dialogue where sharply brought into relief when I proposed to do a free HIV testing day in the Kungba settlement camp in Jorpati (the nearest settlement camp to Boudha). In hindsight, I recognize how naïve my proposal was, as I failed to do exactly what I am recommending in this paper: to develop a more complete understanding of how HIV/AIDS is

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[29] Tsering Dorjee, interview by author, Patan (November 19, 2009).
[30] Hans-Peter Kohler, Stephane Helleringer, "Social networks, perceptions of risk, and changing attitudes towards HIV/AIDS: New evidence from a longitudinal study using fixed-effects analysis," *Population Studies* (Population Investigaton Committee) Vol. 59, No. 3 (2005): p. 267.
[31] Ibid., p. 280.
[32] Ibid., p. 271.

perceived by Tibetans before establishing awareness or prevention programs. However, my experience can point to both how little empirical data there is regarding HIV/AIDS in the Tibetan community, and to how perceptions are formed and defended in the absence of such data. After a week of meetings and telephone conversations back and forth with the secretary for the "main head" of the Kungba camp, we learned that he was uninterested in our offer, claiming that no one in his camp had HIV, thus abrogating the need for the testing.[33] I pressed further, asking if testing had ever been done to determine that no one had HIV. I learned that no testing had been done previously but that the "main head" would know if anyone had HIV. Such a perception of the presence of HIV highlights how little is known among Tibetans in Nepal and how critical it will be to establish dialogue on the issue.

Tibetan health-care professionals are also forced to make conclusions and speculations unsupported by empirical research about the prevalence or causes of HIV/AIDS within their community. Dr. Tenzin Kunga of Kailash Medical & Astrological Society in Chetrapati, told me that with "no data, no screenings, and no specific knowledge" about the prevalence of HIV/AIDS, he gets most of his information by "word of mouth from other doctors."[34] In an email message, Dr. Tenzin Namdul, the director of the Dharamsala based HIV/AIDS organization CHOICE, confirmed that even with no "specific information or data about HIV/AIDS [among Tibetans] in Nepal," he believed it to be a problem, citing the "huge number of Tibetan people going back and forth to India."[35] Doctors are also forced to speculate about the mode of HIV contraction. Dr. Deckyi Yangzom, also of the Kalaish Medical and Astrological Society, explained to me that of the three HIV positive Tibetans that came to the clinic for treatment, she

[33] I was working with Kunsang Lama, project manager of Helping Hand.
[34] Dr. Tenzin Kunga, interview by author, Kathmandu (November 18, 2009).
[35] Dr. Tenzin Namdul, email message to author (November 22, 2009).

had no records for how they contracted HIV and was left to guess that sex was how they contracted HIV.[36] Dr. Namdul also speculated that unsafe sex is the primary mode of HIV transaction among Tibetans in Nepal.[37]

However, Dr. Tenzin Neljor, also of the Kalaish Medical and Astrological Society, held a different perception of the prevalence of HIV/AIDS among Tibetans in Nepal. Although he admitted to having "not much idea" on how many Tibetans live with HIV, he did not think that HIV was very prevalent. He told me that all of his friends use condoms when they have sex, and therefore assumed that all Tibetans are very alert to the risks of HIV.[38] The problems in drawing from a small selection of the Tibetan population, specifically his friends, to represent the entirety of HIV/AIDS awareness among Tibetans in exile did not seem to problematic to Dr. Neljor. If Tibetan medical professionals do not arrive at a consensus on prevalence of HIV/AIDS among their own community, it is hard to expect the Tibetan laity to possess better knowledge. Community health providers are the front line educators. They must posses a more unified and supported perception of how common HIV/AIDS is in their own community in order to control the spread of HIV/AIDS

[36] Dr. Decki Yangzom, interview by author, (November 17, 2009). Sexual transmission of HIV is thought to be the primary way of HIV contraction in India, according to Phuntsok Chomphel, project officer of the Dharmsala based HIV/AIDS organization CHOICE. Lobsang Wangyal, "Tibetan AIDS patient dies on World AIDS Day," *Tibet Sun*, December 1, 2009.
[37] Dr. Namdul expressed that "Tibetan society tends to be a bit more casual with sex," as sex used to be "pretty common in former times in Tibet." Yet he maintained that this might be a concept generally based on views of Tibetan elders and may not hold up among the younger generation. This was one area that I did not have the means to look into further, but a behavioral study on younger Tibetan sexual patterns could be very interesting and informative.
[38] Dr. Neljor's lack of understanding of the HIV/AIDS became obvious to me when he informed me at the end of our interview that HIV/AIDS originally "came from people having sex with monkeys." Dr. Neljor told me that they "had bad intentions, that is why they got HIV." Dr. Tenzin Neljor, interview by author, (November 17, 2009).

At left, a man becomes the "world's fastest kisser," kissing 130 men in under a minute to end discrimination against HIV/AIDS in Nepal. The event was hosted by the National Center for AIDS and STD Control (NCASC) to mark World AIDS Day on December 1st, 2009. Although a similar stigma exists in the Tibetan community in Nepal, efforts aimed to reduce the stigma surrounding HIV/AIDS among Tibetans have not occurred.

"The stigma is everywhere"

"If I told anyone, my mom might find out. If she found out, she would die," Tashi explained to me. Tashi found it challenging enough to confront her parents with the fact that she was a drug user and wanted help. Her neighbors gossiped, she heard rumors about herself that claimed she was "sleeping around a lot," and in any argument, her mother would always bring up the fact that she was a drug user, despite the fact Tashi was seeking rehabilitation treatment. "She would say to me, 'you don't know anything. If you knew anything, you wouldn't have used drugs.'"[39] Tashi decided not to tell anyone except her father and her boyfriend about her HIV status, rationalizing that it was hard enough to live as a recovering drug user in conservative, tight-knit Tibetan society.

The stigma associated with the risk behavior (primarily drugs and sex) attached to HIV/AIDS is overwhelming and keeps many Nepalese and Tibetan alike living in silence about their HIV status. However, this stigma is not unique. Such stigma was dominant when HIV/AIDS first emerged in the U.S. and while lesser now, it certainly still remains. Peter Aggleton et. al describe stigmatization as a "process of devaluation rather than a thing," a

[39] Anonymous, interview by author, Patan (November 21, 2009).

process that is created and reinforced by social inequality.[40] Similarly, Jeannette R. Ickovics understands stigma something that must be studied from an ecological perspective, one that views stigma and discrimination as a "social phenomenon and helps to examine pathways, with a view to find effective and sustainable solutions."[41] It is this process or social phenomenon that is responsible for muting dialogue about the disease. What is unique about the stigma in the Tibetan community is that no one is addressing it. By not addressing this stigma, what it looks like, and where it is derived from, one will not develop a complete understanding of how Tibetans perceive and interact with HIV/AIDS.

One reason the stigma associated with HIV/AIDS is particularly strong is because of the smallness of the Tibetan community in Nepal. I asked Karma Phuntsok what the stigma surrounding drug use was like in the Tibetan community. In his puffy winter coat and with a cigarette held to his mouth, he moaned that, "People don't give you hugs, people turn away from you. They will always think that we are addicts and bad people."[42] I jotted his responses down in my notebook, not noticing that a Tibetan woman had peered over the fence, separating us from the road. She spoke in Tibetan with Karma, then smiled at me and left. "See, the stigma is everywhere," Karma told me. "She thought that I was still a drug user and didn't think that you should be hanging around with me." Karma told me that he did not even know the woman. "I have been clean for nine months, but it doesn't matter," he told me. To Karma, this interaction was unexceptional; yet it proved to me how the negative stigma associated with drug use is

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[40] Peter Aggleton, Richard Parker, Miriam Maluwa, "HIV and AIDS Related Stigma, Discrimination, and Human RIghts: A Critical Overview," *Health and Human Rights* (The President and Fellows of Harvard College) 6, no. 1 (2002), p. 4.
[41] Jeannette R. Ickovics, *HIV-Related Stigma and Discrimination in Asia: A Review of Human Development Consequences*, (UNDP, 2007).
[42] Karma Phuntsok, interview by author, Patan (November 19, 2009).

reinforced again and again as a consequence of the smallness of the Tibetan community in Nepal.

A negative stigma exists even for those who did not contract it through drug use or commercial sex. Sonam contracted HIV from her husband, yet she is still a victim of discrimination. "My landlord knows," Sonam told me.[43] Her landlord threatens to use his knowledge of her HIV status as blackmail, telling her that he will "kick her out" whenever he wants to. Sonam's fear of her status being disclosed and leaked to members of the community, like her landlord, kept her from being tested for over five years after her husband's death. The stigma lies at the foundation of how Tibetans perceive the issue of HIV because it hinders individual's willingness to discuss the issue with their peers and with medical professionals. An understanding and acknowledgement of how deeply rooted the stigma attached to HIV/AIDS is essential to create and implement HIV/AIS awareness and prevention programs.

"We had no jobs. We had nothing else"

When I asked Karma Tenzin why he started using intravenous drugs, it did not take him long to answer. "We had no jobs. We had nothing else," he responded tersely. Karma Tenzin, Karma Phuntsok, and Tsering Dorjee each told me similar stories of their initiation into using injecting drugs. Karma Phuntsok had just finished secondary school and had no future prospects when he began using drugs. Tsering Dorjee was tired of searching for work and found drugs as a way to pass the time. To each of them, the issue at hand was quite simple: If there were more jobs available for Tibetans, they probably would not have started using drugs.[44]

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[43] Anonymous, interview with author, Kathmandu (November 24, 2009).
[44] Tsering Dorjee, Karma Phuntsok, Karma Tenzin, interview by author, Patan (November 19, 2009).

The correlation between unemployment and drug usage is difficult to determine and I was I was tentative at their oversimplification of such a complicated relationship. Adding ethnicity and refugee status to the equation only makes the relationship more convoluted. There are many factors at play when one decides to begin using drugs. Karma and his friends admitted that their lack of employment status was not the only reason they began using injecting drugs. Without jobs, they explained that they fell into a group of friends that was using drugs, they were young and eager to experiment, and no one was telling them not to.[45] Yet, they maintained that a lack of job opportunities for young Tibetans in Nepal was the most dominant factor in their introduction to drug use.

To understand the Tibetan situation with regard to HIV risk factors, their status as political refugees and potential risks to HIV/AIDS that this status poses must be explored further. The twenty thousand Tibetans that reside in Nepal are bereft of any legal status. Nepal is not a signatory to the 1951 UN Convention on Refugees, nor is it part of the 1967 Protocol relating to the State of Refugees, thus it does not recognize Tibetans' rights as refugees under the principal treaties that govern their status under international law. Tibetans in Nepal are stateless, being neither citizens nor legally recognized refugees. The impact that this status has on Tibetans seeking employment, never mind fair and equal protection of basic civil and human rights, is staggering.

One of the most critical rights that Tibetans are denied as refugees are equal rights to own property and to employment. Without Nepali citizenship, Tibetans are denied the right to own

[45] Tsering Dorjee, Karma Phuntsok, Karma Tenzin, interview by author, Patan (November 19, 2009).

houses, cars, land, or other forms of property.[46] This includes ownership over small shops and restaurants in most cases. Thus, many Tibetans recruit their Nepali friends to purchase land, buildings, houses, shops, or restaurants in their name or pay bribes to Nepali police officers to allow them to keep their business.[47] Tibetans are also denied access to any government job in Nepal and any job that requires proof of Nepali citizenship. Tibetans without a refugee identification certificate (RC) have an even harder time finding work.[48] Nepali employers fear hiring undocumented refugees, as it could put them at great risk. As a result of these employment requirements, many Tibetans in exile in Nepal —both with RCs and without— are unemployed.

While there are no official reports of unemployment rates among Tibetans in exile in Nepal, it is assumed to be quite high. Mr. Dhundop Tsering Lama predicts the unemployment rate for Tibetans to be over 60%, illustrating how difficult it is for Tibetans to get jobs without Nepali citizenship.[49] Of those employed, he thinks most work as small shop keeps, cyber café owners, hotel staff, and restaurant owners, or in the remaining small carpet factories.[50] Yet, carpet factories that used to employ a significant portion of the Tibetan exile community are not as large as they used to be. Khamsum Wangdu was one of the biggest Tibetan carpet factory owners in Nepal. He used to own four factories, employing over 600 Nepalese and Tibetans.

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[46] Tibet Justice Center, *Tibet's Stateless Nationals:Tibetan Refugees in Nepal*, (Tibet Justice Center, 2002), p. 4.
[47] Dhondup Tsering Lama, interview by author, Kathmandu (November 24, 2009).
[48] In 1989, under pressure from the Chinese government and as a result of the growing number of new arrivals in Nepal seeking to reap the benefits of the Nepal's thriving carpet industry, the Nepali government stopped administering RCs to new arrivals. The majority of Tibetan exiles since 1989 have used Nepal as a transit country in mark to India, however, there remain a large population of Tibetan refugees (especially those that live outside the settlement camps and those that arrived after 1989) that remain undocumented in Nepal. Mr. Dhundop Tsering Lama, the Settlement Officer for the Tibetan community in Boudha, estimates that of the 20,000 Tibetans in exile, only 13,000 to 14,000 possess RCs. Ibid.
[49] Ibid.
[50] Ibid.

Now, he has just one factory that employs only twenty people.[51] Mr. Wangdu attributes the need for this downsizing to two factors. First, the global economic recession has made his foreign clients less inclined to purchase his carpets and secondly, increased government restrictions and demands for "fees" have limited his business.[52] Mr. Wangdu laments that this has unfortunately "left many young Tibetans without jobs."[53]

Unemployment is clearly not an issue that Tibetans face alone. With the unemployment rate in Nepal at 46%, it is problem that is very familiar to many Nepalese as well.[54] Without major industries, there are limited job opportunities for Nepalese. Unlike its powerful neighbor India, Nepal is a small nation, which makes the Tibetan exile situation in Nepal vastly different from that in India. In India, there are not only fewer government restrictions on jobs available for Tibetan refugees, but there are a plethora of more job opportunities. In addition to jobs in major India cities (where many Tibetans are employed in Delhi and Mumbai at call centers), the Tibetan community in India is much larger, estimated at around 100,000. A larger Tibetan community allows for more employment opportunities within the community, from schoolteachers to government work. When comparing employment opportunities in Nepal to those in India, I do not suggest that exile life is tremendously easier in India then in Nepal. Tibetans are a stateless community, both in India and in Nepal, and must cope with the political, economical, and social consequences of that status at all times. Rather, I aim to highlight the

[51] Emily Wax, "Tibetans in Nepal Watch Carpet Factories Succomb to Economic, Political Pressures," *Washington Post*, July 29, 2009.
[52] Khamsum Wangdu, interview by author, (November 25, 2009).
[53] Ibid.
[54] CIA World Factbook, *CIA World Factbook: Nepal*, 2009, https://www.cia.gov/library/publications/the-world-factbook/geos/np.html (accessed November 18, 2009). Unemployment is defined by here as the percentage of the population that is without jobs.

uniqueness of Tibetan exile life in Nepal and draw attention to the enormous difficulties Tibetans face when they hope to gain employment.

Not surprisingly, there are no records estimating how many Tibetan injecting drugs users there are, and thus there are no surveys asking drug users why they began using. Any argument suggesting a correlation between drug use and unemployment among Tibetans in exile is highly speculative. With that caveat, I have found confirmation among Tibetan drug users and IDU support groups that suggest that the relationship between unemployment and drug use is an avenue where future research should be directed.

There have been numerous studies that illustrate the connection between drug use and unemployment among populations around the world. As research methods have improved and allowed hidden populations to be sampled, it has become apparent that drug use in conjunction with the poverty of long-term unemployment, increases the risk of acquiring HIV/AIDS.[55] In a study conducted of American Indian and Alaska native populations, results demonstrated that employment for any period of time reduced one's chances of using drugs and thus, reduced one's risk for contracting HIV/AIDS.[56] Yet, while their research concluded that the ethnic minorities are at a greater risk for HIV/AIDS as a result of limited employment opportunities, their research also stressed that the relationship between drug use, ethnicity, and employment status is complex and that in order to draw any substantive claims, much more research directed towards "untangling the association between these facts" would be needed[57]

[55] Dennis Fisher, Antonio Estrada, Robert Trotter Grace Reynolds, "Unemployment, Drug Use, and HIV Risk Among Indian and Alaska Drug Use," *American Indian and Alaska Native Mental Health Research*, 2000, p. 2.
[56] Ibid.
[57] Ibid, p. 12.

The association between these unemployment and drug use is not always apparent. For example, Tashi beginnings with drugs were not that different than Karma's initiation. Although she had a job at the time when she began injecting heroin, the Tibetan friends that introduced her to drug use were unemployed.[58] However, Tashi had not previously thought of unemployment as a possible root cause of the beginnings of her addiction. Drug use as a result of lack of jobs is a cause for concern for Mr. Dhundop Tsering Lama. He believed that when the youth feel frustrated with their position as being stateless members of society, "they may turn to drugs."[59]

Kathmandu based IDU support groups also understand unemployment to be a major cause for drug use among both Nepalese and Tibetans. Kunsong Dorjee Lama reported that there are many Tibetans that use injecting drugs, and perceived that unemployment was one causal factor.[60] Madhav Adhikari, Program Manager at the Society for Positive Atmosphere and Related Support to HIV/AIDS (SPARSHA), also saw unemployment as a contributing factor in reasons why people turn to drugs.[61] Although SPARSHA does not ask its patients to report how they think they got HIV, Madhav speculated that there is a lot of drug use among the Nepalese and Tibetan younger generation. Madhav explained that there is not an "appropriate space for youngsters to express themselves." If they are not working, they turn to drugs to "indulge

[58] Anonymous, interview by author, Patan (November 21, 2009).
[59] Dhondup Tsering Lama, interview by author, Kathmandu (November 24, 2009). This idea about the youth being frustrated with their position as refugees in Nepal was an avenue that I tried to develop further, however, no one that I met with expressed similar thoughts. That is not to say that such frustrations do not exist or are not a cause for drug use, but it was something that I did not encounter.
[60] He could not offer specific data because Helping Hand does not ask members to list their ethnicity. Kunsang Lama, interview by author, Kathmandu (November 18, 2009). Kunsang Lama, interview by author, Kathmandu (November 18, 2009).
[61] SPARSHA provides primary care treatment to over 1000 PLHA and ART to 700 PLHA. Madhav Adhikari, interview by author, Patan (November 23, 2009).

themselves."[62] Dr. Namdul asserted that most young Tibetans find themselves in a "difficult situation and one of the easiest ways to escape from it is sex and drugs."[63]

This escape to sex and drugs out of frustration and unemployment is an avenue that should be researched further. In addition, the possibility that unemployment probably increases migrant work among Tibetans—increasing the likelihood of drawing HIV/AIDS from outside of Nepal—should be pursued. Particularly because there are no records of drug use, employment status, or HIV/AIDS among the Tibetans in Nepal, it is all the more important to begin to discern exactly what this dynamic is. With a more developed understanding of specific risk factors for Tibetans in exile in Nepal, efforts that aim to raise awareness and increase prevention programs among Tibetans in Nepal could be much more successful.

The Response of the Central Tibetan Administration

The Central Tibetan Administration (CTA) is not oblivious to the risks that HIV/AIDS poses to their population. Although Tibetans' refugee status has left them absent from any data collection in Nepal, the CTA and the Tibetan Department of Health (DOH) claim that they are "doing a lot to improve access and up-scaling access to HIV counseling and testing."[64] In India, the Tibetan Department of Health (DOH) is responsible for seven hospitals and sixty-seven public health centers. They seek to serve the estimated 200 Tibetans living with HIV/AIDS in

[62] Madhav Adhikari, interview by author, Patan (November 23, 2009).
[63] Dr. Tenzin Namdul, email message to author (November 22, 2009).
[64] Tibetan Department of Health, *Health Department Underlines Prevention of HIV/AIDS in Tibetan Communities*, April 10, 2009, http://www.tibet.net/en/index.php?id=817&articletype=flash&rmenuid=morenews&tab=1 (accessed November 17, 2009).

India.[65] The DOH has produced literature aimed at the different levels of literacy in the Tibetan community, conducted numerous HIV workshops where health workers and physicians from different regions have attended. Yet, many have questioned if these efforts are enough. In an article for Phayul, the largest online Tibetan news source, Stanzin Dawa wrote that, "The only awareness programs and prevention interventions visible within the exiled community are information workshops and the dissemination of literature on HIV and AIDS," and that "not much is known about whether these training, materials and communication methods are effective for behavior change or in promoting voluntary counseling and testing."[66]

Even these initiatives, which have experienced only marginal success, have failed to take root in Nepal. The smaller prevention efforts that have been taken, do not address the root of the problem of HIV/AIDS among Tibetans in Nepal. The absence of initiatives that aim to address the fundamental causes of the Tibetan perception of HIV/AIDS is detrimental to controlling the further spread of HIV/AIDS. Mr. Tinley Gyatso, the director of Tibetan settlements in Nepal, offered one example that illustrates the DOH's unsuccessful prevention efforts in Nepal. He explained to me that this past August, the DOH told him to act as a messenger between all local settlement officers and the Tibetan community living in their respective district. The message: the DOH was willing to offer free HIV testing and even free treatment if someone discovered that they were HIV positive. The DOH could not bring testing centers to the Tibetan settlement camps, but if someone brought their receipt to the Tibetan Settlement Office in Kathmandu, the DOH would reimburse them. Unsurprisingly, not a single Tibetan asked for reimbursement from the DOH.

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[65] Lobsang Wangyal, "Tibetan AIDS patient dies on World AIDS Day," *Tibet Sun*, December 1, 2009.
[66] Stanzin Dawa, "HIV/AIDS and Human Rights," *Phayul*, March 26, 2006.

"No one turned up," Mr. Gyatso stated. "The disease is one that people don't want to show in public. It has a bad association."[67] Mr. Gyatso, as I have already noted, is correct: the stigma associated with drug use and sex is large, never mind the stigma attached to HIV/AIDS. Such stigma could have easily been one of many reasons why the DOH's efforts failed. However, the situation is not one-dimensional and the DOH's offer for free testing did not accurately reflect the complexity of the problem of HIV/AIDS among the Tibetans in Nepal.

Providing free testing was not the answer, at least not to a population that has little knowledge about HIV/AIDS and hugely stigmatized associations with behaviors that can lead to the contraction of HIV/AIDS. The DOH did not attempt to address the conditions that were limiting Tibetan's perception of the disease, nor did they address specific at risk populations within the Tibetan community, both strategies that could have yielded greater results. Further, the DOH did not consider the lack of trust that many Tibetans hold in the confidentiality of the health-care system. In an email correspondence, Chris Hagerty of the Burnet Institute, a group conducting surveillance work on HIV in Lhasa, cited Tibetans' general lack of trust in the confidentiality of health care system and advocated that any prevention effort "must advocate for better, more confidential systems."[68] Although the DOH maintained that all test results would be confidential, convincing individuals of this is different than just advertising it. The efforts by the DOH failed because they did not address Tibetans perceptions of the medical community and the public, nor did these efforts address specifically those that are most at risk for HIV, the preexisting perceptions of the prevalence of HIV and risk of HIV transmission, and the stigma associated with HIV/AIDS that would limit Tibetan's willingness to get tested.

[67] Tinley Gyatso, interview by author, Kathmandu, (December 1, 2009).
[68] Chris Hagerty in an email to author, (November 22, 2009)

A pharmacy and health clinic in Boudha advertises phone call and photocopy services. In order to gain a broader understanding of Tibetans' perceptions of HIV/AIDS, the medical community must foster a more confidential environment conducive to dialogue of highly stigmatized issues.

Recommendations for Future Research

Initiating HIV testing often appears like a good start to addressing the issue of HIV/AIDS. "It's a simple answer," Tsering told me. "Get doctors in here. Do testing."[69] He was determined that with available HIV testing, the fight against HIV/AIDS in the Tibetan community in Nepal could be strengthened. At the time, I nodded in agreement. Of course the answer was to get doctors into the camps, I had thought. If no one knows that they are HIV positive, how will the disease ever be defeated? However, I realize now that fighting HIV/AIDS among Tibetans is less about the fight; rather, it is more about developing a greater understanding of the disease, of the risk factors that Tibetans face, of how they perceive the prevalence of the disease and their own risk factors, and of stigma associated with the disease.

Address Preexisting Perceptions

"You must convince them first. Then you can do testing," Mr. Tinley Gyatso stated, in regard to why the DOH's free testing offer failed. "Convince them that it is a problem, then give

[69] Tsering Dorjee, interview by author, Patan, (November 19, 2009).

them testing."[70] However, because there is such little is known about the "problem," even among health care professionals and government officials, this is much easier said then done. Before prevention and awareness efforts can be affectively implemented, a greater understanding of the way in which Tibetans perceive HIV/AIDS and their individual risk for contraction of HIV/AIDS is essential. Simply offering free testing will accomplish little if individuals' perception of their risk for HIV is low. Thus, before prevention efforts, testing, or awareness initiatives are undertaken, a more comprehensive understanding of how Tibetans actually behave and perceive their risk for HIV is critical.

In a study conducted in Southern Zambia by Stuart Gillespie et. al of local perceptions of HIV risk and prevention, the authors found that the preexisting perceptions and beliefs about HIV play a crucial role in the success of any prevention efforts.[71] They examined the ways in which risks posed by HIV were perceived and acted upon at different levels, the structural obstacles to lowering susceptibility, and local perceptions of existing prevention approaches. Among their findings, they found that a "clear understanding of individual and community perceptions of the factors underlying HIV transmission is essential in order to strengthen prevention efforts."[72] They concluded that more attention must be given to individual agency as an obstacle to prevention strategies. In addition, Tony Barnett and Justin Parkhurst argue that understanding the context of "socioeconomic and cultural realities in which sexual behaviors are shaped" is necessary in order to implement successful prevention and awareness programs.[73]

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[70] Tinley Gyatso, interview by author, Kathmandu, (December 1, 2009).
[71] Stuart Gillespie, Petan Hamazakaza, Elizabeth Byron, "Local Perceptions of HIV Risk and Prevention in Southern Zambia," (2006).
[72] Ibid., p. 9.
[73] Justin Parkhurst, Tony Barnett, "HIV/AIDS: sex, abstinence, and behavior change," *Lancet Infectious Diseases* 5 (September 2005): 592.

Future HIV/AIDS initiatives among Tibetans in exile will benefit from the findings of this research. Before simply telling people to get tested for HIV, there must be greater initiatives to understand how Tibetans perceive the issue. With a better understanding of this perception, prevention and awareness efforts can be better aimed to address this perception and thus be more effective. I hope that my findings can offer a jumping off point to future researchers, but the limitations in my research were large. The kind of research that Gillespie et. al conducted, a survey aimed at identifying individual and community perceptions of HIV/AIDS and strategies to prevent HIV transmission, could help to identify what these perceptions are about HIV/AIDS.

One very pragmatic way to start better understanding how individuals perceive their risk for HIV is to focus on changing Tibetans' relationship to the medical community. If Tibetans can find a safe, private space to discuss risk behavior associated with HIV/AIDS and their own perceptions of such risk, it would be a small but important step to increasing dialogue on the issue. If Tibetans can trust the medical community, it will offer greater insight into how Tibetans perceive the issue of HIV/AIDS and thus form the necessary foundation for future initiatives at combating HIV/AIDS within their own community.

In addition to changing Tibetans trust in the confidentiality of the medical system, creating more safe places to discuss HIV/AIDS and associated risk behavior could be really helpful. Support groups for Tibetans living with HIV, similar to the support groups established by AIDS organizations for Nepalese living with HIV/AIDS could be incredibly valuable. In Nepal, the use of ex-IDUs as peer educators has played an important role in drug intervention programs.[74] Similarly, the use of Tibetans living with HIV as peer educators could be useful to

[74] Sujata Rana, Karl Dehne Andrew Ball, "HIV Prevention among Injecting Drug Users: Responses in Developing and Transitional Countries," *Public Health Reports* 113 (June 1998): 178.

combat the stigma associated with the disease. Tibetan support groups could be very advantageous in conducting more research on how Tibetans perceive their risk for HIV, however, a belief in the confidentiality of these groups and of the larger medical community is crucial.

Conduct Sensitive Surveillance

The decline in number of HIV positive drug users in Kathmandu is noteworthy. When I asked Dr. Rai of the NCASC, he confirmed that the same techniques and strategies responsible for this decrease could be applied to Tibetans as well, such as greater awareness campaigns, harm reduction efforts, and prevention programs. However, he demanded that before such efforts can be instigated, "you need an assessment of the situation. You need a starting point."[75] In addition to research initiatives on how Tibetans perceive their risk for HIV/AIDS, surveillance conducted on Tibetans living in Kathmandu about the prevalence of HIV/AIDS and behavioral surveys about high-risk HIV behavior could offer unique insight into the issue.

One way in which to start obtaining data about the prevalence of HIV/AIDS among Tibetans is to call on the support of existing groups that work with HIV/AIDS in Kathmandu. If existing AIDS groups and networks were encouraged to keep data on the ethnicity of their members (recorded anonymously), this would provide a good starting point to gaining an understanding of the prevalence of HIV/AIDS among Tibetans. Dr. Rai expressed that if NCASC can be convinced that the issue of HIV/AIDS among Tibetans in Nepal should be studied, NCASC would be interested in conducting such studies. I was very surprised at this remark, considering that NCASC is government funded. However, Dr. Rai assured me that this

[75] Krishna K. Rai, interview by author, Kathmandu (November 26, 2009).

research would not encounter problems. "HIV/AIDS is a human rights issue," he declared, perhaps too idealistically.[76] Understanding the complexity of the issue is the first necessary step towards developing solutions that will adequately meet the problem. Talking to those that are living with HIV, creating forums and safe places for this discussion to occur organically, and questioning the causes behind their experiences living with HIV is critical to obtaining a more complete understanding of the issue.

Conclusion: "To be treated normal"

Tashi walked me to the door, I thanked her again, we hugged, exchanged phone numbers. As I left, I felt like I had made a new friend, someone who trusted me enough to confide in me, to share a deeply held secret, to cry comfortably in front of. I was struck by her eagerness to share all of this with me, a college student passing through Nepal for a few months, hoping to pursue some sort of meaningful research on a catchphrase topic that had become a defining component in her life. She did not hesitate at any of my questions, but rather addressed them directly and with answers that almost seem prepared. Tashi even began to ask me questions: Who was I? What was I doing in Nepal? Why was I interested in her? Our interview became a conversation, one that was guided by mutual curiosity and interest.

While I can only speculate, I think that this was a conversation that Tashi was waiting to have, perhaps yearning for someone to care about her story. I could not help but be struck by the somberness of our interview as Tashi cried over the way her mother treats her, as she told me that her one wish was "to be treated normal" again, as she explained that she wished she could

[76] Krishna K. Rai, interview by author, Kathmandu (November 26, 2009).

"go back in time" and never start using drugs.[77] However, this conversation also offered me hope for Tashi's future. Tashi's willingness to discuss these issues with me – an outsider to her community that was interested in her story –in a safe place, free from the judgment and stigma that she had become engrained in her life since she was seventeen inspired me. I got the impression that Tashi didn't feel comfortable having this kind of discussion with her peers, knowing how most Tibetans react to this kind of news. Ironically, our very distance as strangers made it possible for us to hear one another.

[77] Anonymous, interview by author, Patan (November 21, 2009).

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