Perspectives on Hepatitis B in Tibetan Refugee Communities

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EXECUTIVE SUMMARY

Why this is important?

Despite the prevalence of Hepatitis B in Tibetan populations, little is known about how Tibetans perceive of Hepatitis B, how they deal with it, and how stigmatizing it may be. These perspectives are important to know and to integrate into public health programming around Hepatitis B.
Objective
This project represents a rapid qualitative inquiry to better understanding Hepatitis B in the community and public health context of settlements administered by the Central Tibetan Administration.

What we did?
Qualitative interviews and focus groups with 296 individuals. Field debriefing and thematic analysis identified themes and patterns that led to our findings and recommendations.

Main findings
Qualitative interviews and focus groups not only helped the project better understand community health concerns, but they also provided important findings about how the work was done that provides helpful lessons for future projects and research. Participants describe a complicated set of notions around Hepatitis B transmission that integrate and sometimes conflate genetics and maternal-child transmission. Cultural notions around diet, transmission, and alcohol are common among Tibetan refugees when discussing Hepatitis B and could map to preventive strategies promoting key Hepatitis B messages. Refugees with and without Hepatitis B frequently cited cost/availability of allopathic (“Western” or “Indian”) medications as a major concern. While Tibetan refugees infrequently report stigma and discrimination toward people living with HB, they face stigma in healthcare and employment contexts and from those with HB misconceptions.

Recommendations
1. The Health Department should create a comprehensive Hepatitis B program that focuses on culturally effective prevention, diagnosis, and treatment of Hepatitis B in a non-stigmatizing manner.

2. Explore, design, and test messaging and materials around how to best communicate prevention, diagnosis and treatment of Hepatitis B, respecting local beliefs and world views. Include the design of creative methods for implementing these culturally sensitive messages into health encounters and non-health encounters.

3. Explore the creation of sustainable partnerships that enhance the availability and access to medications (both allopathic and Tibetan).

4. Continue to engage with the global community to increase visibility of the situation of Tibetans living in exile and its effect on health.
BACKGROUND

State of the problem
The burden of Hepatitis B is well-documented in Asian populations and is particularly acute with Tibetan populations living outside of Tibet. Despite efforts to treat Hepatitis B and prevent transmission in Tibetan refugee populations, its prevalence remains high. A recent assessment of Hepatitis B by the CTA and Johns Hopkins University showed an 11.9% chronic Hepatitis B prevalence. The World Health Organization defines as “high” the prevalence of a disease in more than 8 percent of the population. As an indigenous community-in-exile, Tibetan refugees may be missed by Hepatitis B control interventions that target culturally different host communities.

What we need to know
Despite the prevalence of Hepatitis B in Tibetan populations, little is known about how Tibetans perceive of Hepatitis B, how they deal with it, and how stigmatizing it may be. These factors are important in creating effective strategies to control Hepatitis B in Tibetan refugee communities.

KEY FACTS

- Hepatitis B is a viral infection that attacks the liver and can cause both acute and chronic disease.
- The virus is transmitted through contact with the blood or other body fluids of an infected person.
- An estimated 240 million people are chronically infected with hepatitis B (defined as hepatitis B surface antigen positive for at least 6 months).
- Approximately 780,000 persons die each year from hepatitis B infection — 650,000 from cirrhosis and liver cancer due to chronic hepatitis B infection and another 130,000 from acute hepatitis B.
- Hepatitis B is an important occupational hazard for health workers.
- Asian populations are especially at risk with Tibetan refugees having high infection prevalence (8.9%).

However, it can be prevented by currently available safe and effective vaccine.

METHODS

Our team

A multidisciplinary team was assembled consisting of Central Tibetan Administration (CTA) public health officials and workers, Tibetan nurses, and foreign partners to conduct group and individual interviews with Tibetans residing in CTA-administered settlements in Ladakh. Team members completed CITI Program human subjects training and an on-site ethics briefing. Funding for the project was provided by the Hershey Family Foundation.

Community engagement and respect

Given the nature of this project as a qualitative examination of health-related issues targeting the development of CTA programs, obtaining community input and understanding culture was a priority. The project team from the US are experienced with qualitative methods, with Tibetan and indigenous populations, and completed a week-long planning visit with the Tibetan partners in Dharamsala. Dr. Dye is a medical anthropologist with field experience in more than 20 countries and is familiar with community engagement, cultural sensitivity, and ethical qualitative practice. The investigator from the Tibetan team, Dr. Wangchuk, is the Health Kalon for the CTA, ensuring that the project was accountable to the highest levels of government. During the first day’s training with the combined US and Tibetan team, we covered general issues around interviewing with the specific protocol we developed for this project, ethical issues as they relate to participant rights, confidentiality of information, and team dynamics. We debriefed daily and any team or other issues that arose were handled with the appropriate staff, taking our lead from our Tibetan counterparts.
What we did

Qualitative interviews and focus groups helped the project better understand community health concerns, cultural conceptions around Hepatitis B, illness narratives of participants living with Hepatitis B, and the public health context of these issues. The project included six layers of approval and consent including: 1) the Central Tibetan Administration Health Kalon; 2) University of Rochester Research Subjects Review Board; 3) University of Hawaii at Mānoa Human Studies Program; 4) Ladakh Sonamling Tibetan Settlement Officer; 5) Individual Refugee camp leaders; and 6) individual consent was given by each individual participant.

Recruitment

We were specifically interested in talking with people about Hepatitis B. We wanted a mix of individuals who had been diagnosed with Hepatitis B, had family members with Hepatitis B, and individuals who did not have Hepatitis B. Communities were aware of our presence and we worked with CTA health clinic and administrative personnel who have routine access to population information in locating people to interview.

Staff of the Primary Health Center that serves the Tibetan refugees also contacted people who tested positive in their Hepatitis B screening program to invite them to consider participating in an interview.

This study involves: community observations/walkthroughs and qualitative interviewing (individually, and in groups).
Community walkthroughs

Community walkthroughs were guided by local partners. The purpose of the walkthroughs were to understand the community geography, visit local institutions (clinics, schools, social spaces). The team visited numerous cultural sites of importance, including monasteries, markets, local restaurants, and walking tours of various areas. These visits helped underscore the importance of cultural, political, and circumstantial influences that may impact health, the development and implementation of this particular assessment, and overall health improvement. The walkthrough resulted in the following:

- Engaged stakeholders in the project and its priorities
- Refined the methodology
- Helped us understand the community and family factors in Hepatitis B prevention and education
- Helped the team better understand the importance and role of unique cultural circumstances and institutions, such as the Tibetan Children’s Village (TCV) system.
Qualitative interviews

A single interview guide was used for all interviewing activities, as a qualitative method, and to stimulate conversation around topics the participant(s) felt were related. Group discussions covered portions of the interview guide, which was designed to stimulate a range of discussions. The purpose of the qualitative interviews was to help the project better understand community health concerns, cultural conceptions around hepatitis B, illness narratives of participants living with hepatitis B, and the public health context of these issues. To do this questions were asked to help individuals articulate:

- Conceptual models of Hepatitis B (from Kleinman et al 1978)
- Illness narratives from the McGill Illness Narratives Instrument (MINI) adapted for Tibetan populations (from Craig et al. 2010)— illness narratives capture the symptom and illness experience and explanatory models for what causes the disease, expectations for treatment, course and outcome.
- “Grand tour” questions (Spradley 1979)— basically a verbal tour of something they know well. The major benefit of the question is that it gets respondents talking, but in a fairly focused way.

Any or all of these questions were used in a particular interview, or group interview. Qualitative interviews, however, were participant-driven; the interview covered a range of topics that the participant wished to discuss.

Interviews were generally conducted in oral Tibetan, though many participants spoke English additionally so some interviews mix the two languages. The Tibetan project team are ethnic Tibetans with Tibetan as their native language, and all are also fluent in English. Fluency in written Tibetan is uncommon with many of the participating population, so most activities were conducted orally in English and Tibetan.

Analysis

Interviews were audio recorded for translation and transcription. Verbal consent for audio recording was obtained before recording. No names or other identifying details were associated in the audio or written materials. The audio materials were used to create verbatim transcripts and for spot checking translation. Transcriptions and translations were completed by CTA Health Department staff in Dharamsala, India, where the CTA is based.

Field debriefing and thematic analysis identified themes and patterns in explanatory models and illness narratives. In addition, we are currently doing systematic analysis to code all transcripts and prepare our findings for publications in peer-reviewed health journals.
RESULTS

Who participated

We recruited people who have been diagnosed with Hepatitis B and also people who have not been diagnosed with Hepatitis B. Communities were aware of our presence and we worked with CTA health clinic and administrative personnel who have routine access to population information in locating people to interview. Staff of the Primary Health Center that serves the Tibetan refugees contacted people who tested positive in their Hepatitis B screening program to invite them to consider participating in an interview.

| 26 | Focus Groups |
| 41 | Individual Interviews |
| 296 | Total participants (39.7% male, 60.3% female) |
| 27 | Number of participants that were living with Hepatitis B |
| 5  | Number of participants with family members living with Hepatitis B |

What follows are the main findings, implications and recommendations based on the community perspectives gathered through this process. Five major themes emerged around: 1) the process of this project; 2) living in exile; 3) complex illness narratives regarding transmission; 4) barriers to treatment; and 5) stigma.
THE PROCESS

Qualitative interviews and focus groups not only helped the project better understand community health concerns, but also they provided important findings about how the work was done that provides helpful lessons for future projects and research. The group discussions were followed by health education talks by CTA health providers about Hepatitis B and any local concerns were referred to the local health clinic staff.

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<td>People very much enjoyed the group discussion experience and methodology, and the health education that followed.</td>
<td>Group discussion methods integrated into the existing Tibetan health care system and Health Department are effective ways of 1) learning about perceptions and experiences that could impact how public health programs are designed and implemented and 2) engaging and communicating health information.</td>
<td>Wherever possible, systematic group discussions could be used to both:</td>
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<td>1. Learn about community ideas that could impact a particular issue.</td>
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<td>2. Engage and communicate with communities.</td>
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<td>Obtaining appropriate permissions and consent takes time but are important and valued.</td>
<td>Engaging leaders throughout the Tibetan refugee community and health system is important and participants valued that this work was part of a larger effort.</td>
<td>Take time to obtain necessary permissions across all levels of the community to help:</td>
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<td>1. Protect the rights of communities and participants in the research process.</td>
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<td>2. Engage leaders in a wider context around the issues of interest.</td>
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LIVING IN EXILE

Tibetan life in exile defines many aspects of how refugees perceive their health and the causation of poor health.

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<td>Tibetans often ascribe Hepatitis B causation to dramatic shifts in diet precipitated by exile, creating a mismatch of local foods and environmental conditions and Tibetan traditions</td>
<td>While diet and environmental conditions (e.g. weather, lower altitude) are not directly related to Hepatitis B causation and transmission, participants believe they indeed are related.</td>
<td>Where appropriate, weave messages around a healthy “Tibetan” diet and Tibetan ways of eating into Hepatitis B messaging. Think of Tibetan ways of adjusting and accommodating imbalance, which may help address real and perceived environmental differences. These factors are contextual and can help make more direct Hepatitis B messages (around vaccination, safe health practices) better understood and accepted through connection with existing notions.</td>
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While in Tibet, we used to have very good and nutritious foods but now our diet has changed due to the change in society, we rarely eat the most nutritious food of Tibet: tsampa.

Male, 40s, living with Hepatitis B, born in India

Interviewer: What do you think causes Hepatitis B? Participant: Eating of fried foods. If you take more oily and fried foods. We Tibetans have a habit of eating foods like Chowmein, puri (dipped chapatti), momo and thukpa.

-30s, spouse living with Hepatitis B, born in Tibet

It's basically your diet. Old meat, oily food, uncooked meat, old cheese and butter may also lead to Hep B. Mostly in Tibetans because they love meat and these things.

-Female in her 50s, born in India


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<td>Participants describe Hepatitis B as “genetic” with many participants being unclear regarding the nature of genetic transmission. Participants describe a complicated set of notions around Hepatitis B transmission that integrate and sometimes conflate genetics and maternal-child transmission. Consequently, little is perceived to prevent such genetic disease.</td>
<td>Participants understand the general idea of “vertical transmission” (mother-child) of Hepatitis B but not the mechanism, frequently, labeling it “genetic” (understandable since genetic mechanisms are one way a woman can pass characteristics and conditions through to her children through her genes). Genetic situations are perceived as inevitable—so it leads to perceptions that nothing can be done about Hepatitis B.</td>
<td>Creating visual material and messaging that simply describes vertical transmission (perhaps leveraging Tibetan cultural ideas around blood) and refrain from referring to Hepatitis B as genetic. Unlike community perceptions about diet and environmental disbalance previously described as affiliated with Hepatitis B, there are not contextually positive messages that could address the misperceptions around Hepatitis B being genetic (and therefore, inevitable).</td>
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Participants describe a complicated set of notions around Hepatitis B transmission that integrate and sometimes conflate genetics and maternal-child transmission.

People say that it is hereditary, that if the parents have it, the children get it too. And when we tested people for Hepatitis B, it has generally been seen that if parents have Hepatitis B, all the children also have it.

-50s, spouse living with Hep B, born in India)

Generally some parents have it and some not. Some people say that it is genetic. But if it is genetic then some children have it and some not. So I don’t understand the point.

-Male, 60s, with hepatitis, from Tibet)

Most of the cases are family related hereditary. Yet there are cases where parents don't have Hep B but their child have it. Or, sometimes there are parents with Hep B but only couple of children among five or six have it. There are also cases where one of couple has it and other doesn't have it.

-Female, 40s, with hepatitis; born in India)
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<td>Hepatitis B is a salient, important health issue during pregnancy among Tibetan refugees. Participants who were Hepatitis B positive commonly indicate others in their family, including their mother, also have Hepatitis B, implying that maternal-child transmission may be frequent among women of childbearing age.</td>
<td>Pregnancy offers a unique opportunity for Hepatitis B education, prevention, screening, and treatment. Pregnancy often leads to more encounters with health providers and directly introduces thought around the woman’s own health, and the health of her infant.</td>
<td>Target pregnancy as a opportunity to reach women and their infants, and to provide education and intervention to family members. Perhaps consider a specific set of public health actions that can be organized around Hepatitis B and pregnancy, potentially reaching more people for a longer period.</td>
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<td>Women often learned their Hepatitis B status during pregnancy through routine screening, a diagnosis that creates fear and anxiety over the woman’s and her infant’s subsequent health, including fear around their ability to pass the disease to others.</td>
<td>Because Hepatitis B is often diagnosed in pregnancy (because, as explained above, there is greater opportunity for diagnosis with the increase in health encounters accompanying pregnancy care), women could delay or avoid pregnancy care around fears of learning their Hepatitis B status.</td>
<td>Consider a more broad public health campaign aimed at learning one’s Hepatitis B status, and reducing the stigma associated with learning of a positive status. For instance, programs have been developed and implemented around HIV focus on “know your status” in the general population, which can reduce stigma and anxiety and lead to needed medical care and prevention education.</td>
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<td>Participants frequently expressed relief that a vaccine is available for newborns which may reduce the spread of HepB in the community.</td>
<td>People value newborn immune globulin and understand that it is helpful and may help alleviate anxiety around Hepatitis B.</td>
<td>Enhance existing efforts to assure that all newborns are appropriately vaccinated against HepB and other illnesses.</td>
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**COMPLEX ILLNESS NARRATIVES - PREGNANCY TRANSMISSION**

Interviewer: Is it through the breast milk or during the delivery? Participant: During the conception. The baby already gets the disease in the womb.

-Female in Focus Group

Female: It is very problematic to them. They can't be with their own baby after delivery. They are kept in different room. Unable to breast feed the baby and problem of breast feeding the baby from others. And there are problems in every regards... becoming thin and unable to eat food. According to my experience I feel it is a very sad and miserable situation.

-Female in Focus Group
COMPLEX ILLNESS NARRATIVES - AN OPPORTUNITY

Cultural notions around diet, transmission, and alcohol are common among Tibetan refugees when discussing Hepatitis B and could map to preventive strategies promoting key Hepatitis B messages.

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<td>Public health professionals can build onto existing beliefs surrounding Hepatitis B to more effectively engage refugees.</td>
<td>Change—especially in thoughts and beliefs—is difficult or impossible in many communities. Expressing desired health behaviors using cultural language (references, beliefs) increases the likelihood that community members will understand and enact the preventive and treatment behaviors needed.</td>
<td>Rather than focusing on a health education model that fully challenges and replaces “traditional” ideas with contemporary notions around viruses and their treatment, consider blending or expressing contemporary health education messages in a traditional context, using Tibetan reference points and expressed in Tibetan ways. This approach may help facilitate community uptake of health messages, and create a way for enacting new health behaviors.</td>
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This disease is caused by food ...and virus also...Both virus and food. Food...Cow and Yak’s meat...most of the liver diseases are caused by big animal’s meat. And also virus causes this disease.

-Female without Hepatitis B
BARRIERS TO TREATMENT

Refugees with and without Hepatitis B frequently cited cost/availability of modern allopathic medications as a major concern.

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<td>Refugees rely heavily on locally-available Tibetan medicines for Hepatitis B, partially due to inaccessibility of allopathic medicines. While Tibetan medicines cost less, participants noted they were also often cost-prohibitive.</td>
<td>Refugees rely heavily on locally-available Tibetan medicines for HepB, partially due to inaccessibility of allopathic medicines</td>
<td>Create global, local, and regional partnerships that facilitate access to and availability of allopathic and Tibetan medicines that are useful in treating underlying Hep B symptoms.</td>
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| Hepatitis B is frequently identified through screening and when affected people are generally symptom-free | Need for allopathic medication is perceived as less critical | Work towards creating a drug access program for Hepatitis B medications, both allopathic and Tibetan, and promote their access. Further, underscore the importance for both:  
1. Allopathic medication to treat the underlying infection  
2. Tibetan medication to treat symptoms  
Work with practitioners prescribing both to assure integrated promotion. |

We are unable to take Western medicine because we can’t afford it . . . and we don’t have to give medicine to the kids now. So I don’t know the meaning of what they are saying.

- Women in her 50s with Hep B and whose children also have Hep B

Generally saying a poor family can’t afford the treatment since medicines are very costly. If we don’t have any income it’s difficult to afford the cost . . . As for me, my wife and I both work, so I could afford the drug. Anyhow, we will die one day when the time comes.

- Male in his 40s, living with Hepatitis B

Interviewer: What do you think hepatitis does to you? How does it work? Participant: I don’t know. I don’t care about it because I have no money. I don’t know how long I live, or not.

- Female in her 50s living with Hepatitis B, with children who have Hepatitis B
STIGMA

While Tibetan refugees infrequently report stigma and discrimination toward people living with Hepatitis B, they face stigma in healthcare and employment contexts and from those with Hepatitis B misconceptions. Understanding stigma will help healthcare providers, public health professionals, and communities improve Hepatitis B treatment and support.

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<td>People living with Hepatitis B discussed experiencing greater discrimination outside the community, particularly from healthcare workers (e.g. during childbirth, hospitalization).</td>
<td>Stigmatization— directly or indirectly— can impact the lives and care of those living with Hepatitis B. Specifically, if this stigmatization occurs in a health care setting, patients may avoid obtaining care or following treatment regimen.</td>
<td>Work with health care providers to assure that usual precautions taken in health care settings are not perceived as stigmatizing to patients and increase awareness among non-Tibetan health care providers and community members to reduce stigma toward those living with Hepatitis B. There are many lessons form the HIV community around this topic that have helped reduce HIV-related stigma.</td>
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<td>Stigma is complex among Tibetan refugees. Few people living with Hepatitis B report severe stigma within their communities. Most report that Tibetan families and communities support those effected.</td>
<td>Common misconceptions about disease transmission and prevention appear to generate fear and discomfort regarding people living with HB.</td>
<td>More recent awareness and education has helped to reduce stigma around Hepatitis B.</td>
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Some people give me moral support and advice me, but some people try to avoid me as they thought that it might spread to them.

-Woman in her 30s living with Hepatitis B

Few years back, there was this sudden widespread fear of this disease . . . things are better nowadays . . . many people came from the CTA’s Department of Health and even from the State to talk to us and tell us about hepatitis B. So nowadays, people do have an idea about how to get tested for the disease and how to look for treatment.

-Female in her 50s whose husband is living with Hepatitis B
I am old and it doesn't matter but my children have a whole life to spend in front of them...it seems hepatitis positive people don't get jobs...strange...so if it is like this, then even if my children are educated it is useless.

Female in her 50s living with Hepatitis; all her children have Hepatitis

NEXT STEPS
Displaced populations, like Tibetan refugees, face compounded challenges and inequities in treating complex viruses, like Hepatitis B, creating additional burden for disease control within their communities. We propose the following next steps to address Hepatitis B in Tibetan refugee communities:

1. The Health Department must create a comprehensive Hepatitis B program that focuses on culturally effective prevention, diagnosis, and treatment of Hepatitis B in a non-stigmatizing manner.

2. Continue to engage communities to ensure culturally appropriate interventions.

3. Epidemiological surveillance and ongoing qualitative monitoring, around Hepatitis prevalence and incidence should continue to provide helpful information about disease progression.

4. Explore, design, and test messaging and materials around how to best communicate prevention, diagnosis and treatment of Hepatitis B, respecting local beliefs and worldviews. Include the design of creative methods for implementing these culturally sensitive messages into health encounters and non-health encounters.

5. Explore the creation of sustainable partnerships that enhance the availability and access to medications (both allopathic and Tibetan).

6. Leverage the Tibetan values of sensitivity and inclusiveness around care and integration of Hepatitis B positive community members and address stigma issues faced by this population outside of the Tibetan community.

7. Continue to engage with the global community to increase visibility of the situation of Tibetans living exile and its effect on health.
As Tibetans in exile struggling for our freedom, such hepatitis disease could hinder the Tibetan race and harms the growth and overall condition of one’s society.

- Male, 30s, born in a nomadic area
The project team would like to acknowledge the generous financial support from The Hershey Family Foundation for this work and the expertise of OneHEART World-Wide, which participated in initial discussions around project design.