



## AN ABSTRACT OF THE DISSERTATION OF

Jennifer Kue for the degree of Doctor of Philosophy in Public Health presented on May 2, 2011.

Title: Hepatitis B and Liver Cancer Among Hmong: Knowledge, Perceptions of Risk, and Barriers to Hepatitis B Screening and Vaccination.

Abstract approved:

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Chronic hepatitis B disproportionately affects Asian Americans. Although Asians make up only 4.2% of the total United States (U.S.) population, they account for more than half of those infected with hepatitis B. If left untreated, chronic hepatitis B could lead to cirrhosis, liver damage, and liver cancer. Studies show that the Hmong population in the U.S., who emigrated from Southeast Asia where hepatitis B is endemic, have a high prevalence of hepatitis B, yet knowledge about the disease, as well as, screening and vaccination rates, are low.

Guided by the ecological perspective, the Health Belief Model (HBM), and the Explanatory Models Approach, the purpose of this exploratory study was to examine 1) knowledge and beliefs about hepatitis B infection and transmission; 2) perceptions of risk to hepatitis B; 3) barriers to hepatitis B screening and vaccination; and 4) knowledge of liver cancer among Hmong living in Oregon. This study used a mixed

methods approach (i.e., quantitative and qualitative) to collect data from Hmong women and men living in Oregon. Data from 17 key informant and 83 in-depth interviews were analyzed using content analysis techniques.

Results indicated that most in-depth interview participants had heard of the hepatitis B virus (96%) and slightly over half had been screened (53%) and vaccinated (51%). Bivariate analyses showed that education, health insurance, preventive care, doctor's recommendation, and English proficiency were significantly associated with having been screened for hepatitis B. Only English proficiency was significantly associated with hepatitis B vaccination. In general, more than half of the in-depth interview participants were able to correctly identify most of the routes of hepatitis B transmission; however, there were still large gaps in knowledge. Nearly 40% were unaware that sexual intercourse was a route of transmission, 41% did not know that sharing a toothbrush could spread the virus, and 57% did not know that the virus is not transmitted through coughing. Multivariate logistic regression analyses indicated that the relationship between most HBM components (e.g., perceived susceptibility, perceived benefits) was not associated with screening or vaccination. Qualitative results provided insight into screening and vaccination experiences and Hmong beliefs about liver cancer. In general, in-depth interview participants reported not facing many barriers in getting screened or vaccinated for hepatitis B. Some participants cited that not knowing the testing process or the importance of testing made it difficult to get screened. Participants tended to have fatalistic beliefs about liver cancer and remarked that liver cancer signified death or a disease that was incurable. The

findings suggest that Hmong in Oregon have low levels of knowledge about hepatitis B and liver cancer and indicate a need for culturally tailored educational interventions.

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Hepatitis B and Liver Cancer Among Hmong: Knowledge, Perceptions of Risk, and  
Barriers to Hepatitis B Screening and Vaccination

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I understand that my dissertation will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my dissertation to any reader upon request.

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Jennifer Kue, Author

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# Hepatitis B and Liver Cancer Among Hmong: Knowledge, Perceptions of Risk, and Barriers to Hepatitis B Screening and Vaccination

## CHAPTER 1. INTRODUCTION

Hepatitis B is a serious public health issue in the United States (U.S.) (Institute of Medicine [IOM], 2010). Hepatitis B is an infection of the liver caused by the hepatitis B virus (HBV) and can lead to cirrhosis, liver damage, and liver cancer (Centers for Disease Control and Prevention [CDC], 2008c). According to the World Health Organization (WHO) (2010), HBV is 50 to 100 times more infectious than the Human Immunodeficiency Virus (HIV). The CDC (2008c) estimates that 1.4 million people in the U.S. are chronically infected with HBV. If left untreated, one in four chronic hepatitis B carriers will die of either liver failure or liver cancer (WHO, 2010).

Globally, more than 350 million people are chronically infected with the HBV (WHO, 2010), meaning that they are lifelong hepatitis B carriers, as compared to people who experience an acute infection that lasts no more than 6 months. Hepatitis B is endemic in many parts of the world, particularly in Asia, the South Pacific, sub-Saharan Africa, Australia, New Zealand, certain countries in South America and the Middle East, and in certain indigenous populations residing in Alaska, Northern Canada, and Greenland (CDC, 2005; WHO, 2010). In developed countries, HBV is more prevalent in certain groups such as immigrants from endemic countries, injection

drug users, men who have sex with men, and persons with multiple sex partners (CDC, 2004).

Hepatitis B infection is the foremost risk factor for liver cancer (American Cancer Society [ACS], 2007) and contributes to 80% of all liver cancer deaths worldwide (CDC, 2006a). In a prospective study examining hepatitis B among Taiwanese men, Beasley, Hwang, Lin, and Chien (1981) found that individuals with chronic HBV are at more than 200 times greater risk of developing liver cancer than those not infected. Liver cancer, or hepatocellular carcinoma (HCC), is the third most common cause of cancer deaths worldwide (Parkin, Bray, Ferlay, & Pisani, 2005). An estimated one million people die each year from liver cancer (WHO, 2010). Eighty-two percent of liver cancer cases and deaths occur in developing countries, with China accounting for 55% of those cases (Parkin et al., 2005). Although liver cancer is relatively uncommon in the U.S., it is one of the leading causes of cancer deaths among Asian Americans (Miller, Chu, Hankey, & Ries, 2008).

Hepatitis B can be transmitted through blood and bodily fluids, such as semen and vaginal secretions (CDC, 2005). Routes of HBV transmission include: 1) percutaneous or horizontal transmission (e.g., sharing drug needles, tattoos, needle stick injuries, toothbrushes, razors, and close person-to-person contact, possibly by open cuts and sores, especially among children), 2) perinatal or vertical transmission (i.e., mother-to-child), and 3) sexual intercourse (CDC, 2005). Although the virus is highly concentrated in blood, saliva has been demonstrated to be infectious (CDC, 2008c). HBV is not transmitted through coughing, sneezing, or kissing (Asian Liver



Center, 2007). Hepatitis B is largely preventable through screening and immunization. A vaccination series of three shots can give an individual life-long protection from HBV (CDC, 2005). Other preventive measures include vaccinating infants born to chronically infected mothers and education about routes of HBV transmission (CDC, 2005).

This study explored knowledge and beliefs of HBV infection and liver cancer, perceptions of risk of HBV infection, and barriers to hepatitis B screening and vaccination behaviors among Hmong residing in Oregon. Hmong are people from Southeast Asian countries, such as Laos, Thailand, Burma, and Vietnam. Most Hmong in the U.S. are from the country of Laos and are a part of the larger group of refugees that resettled in the U.S. in the late 1970s and early 1980s known as *Indochinese refugees* (e.g., Laotians, Cambodians, Mien, Hmong, and Vietnamese) (Hein, 1995). The Hmong were one of the largest groups of refugees to resettle in the U.S. after the Vietnam War in 1975 (Southeast Asia Resource Action Center [SEARAC], n.d.).

### HBV and Liver Cancer among Asian Americans

In the past two decades, the overall incidence of acute HBV infection in the U.S. has declined dramatically. From 1986 to 2006, the incidence rate of acute HBV infection decreased from 11.2 cases per 100,000 to 1.6 cases per 100,000 (CDC, 2008a). This decline is in large part due to the hepatitis B vaccination, which has been

available in the U.S. since 1982 (CDC, 2008a). In the federal government's strategy to eliminate HBV infection, the Advisory Committee on Immunization Practices (ACIP) recommended in 1991 that all infants receive the three-shot vaccination (CDC, 2005). ACIP's recommendations were broadened in 1999 to include vaccination of all children and adolescents between 0-18 years (CDC, 2005). These new recommendations also called for all pregnant women to be screened for HBV surface antigen (HBsAg) and for postexposure immunoprophylaxis for infants born to HBsAg-positive women. As a result of these recommendations, the greatest decline in incidence rates of HBV infection was among children aged 15 years and younger (from 1.2 per 100,000 in 1990 to 0.02 per 100,000 in 2006, a 98% reduction) (CDC, 2008c). The CDC further extended its hepatitis B screening recommendations in the fall of 2008 to include screening all persons born in geographic regions with hepatitis B prevalence of 2% or greater (e.g., Asia, Pacific Islands, Africa, the Middle East, and Eastern Europe) (CDC, 2008c). According to the CDC, the recommendation expansion was necessary because the highest rate of liver cancer deaths and chronic HBV infection in the U.S. are among foreign-born individuals, specifically from Asia. The CDC reports (2008c) that 47% to 70% of chronic HBV carriers in the U.S. are born in other countries.

It is well documented that HBV infection disproportionately affects Asian Americans. Although the *acute* HBV infection rate has declined for the general U.S. population (1.6 per 100,000 in 2006), as well as for the Asian American population (1.2 per 100,000 in 2006), *chronic* HBV infection among Asian Americans is high

(CDC, 2008a). More than 14 million Asians live in the U.S. and, although they only make up 4.8% of the total U.S. population (U.S. Census, 2011), they account for more than half of the estimated 1.4 million people infected with hepatitis B (Asian Liver Center, 2007). According to the American Liver Foundation (2006), 1 in 10 Asian American is chronically infected. Perinatal and horizontal transmissions are the most common modes of HBV transmission among Asian Americans (CDC, 2006a; Gjerdingen & Lor, 1997; Hurie, Mast, & Davis, 1992; WHO, 2000).

Although compared to other racial and ethnic groups, Asian Americans have lower incidence and mortality rates from all cancers combined, cancer is the leading cause of death among Asian Americans, whereas heart disease is the leading cause of death for non-Hispanic White, African American, American Indian and Alaska Native, and Hispanic populations (ACS, 2008). According to Chen (2005), cancer is unique in Asian Americans because they are the only racial/ethnic group to experience cancer as the leading cause of death in individuals in both age categories of 25 to 44 years and 45 to 64 years. Furthermore, Asian Americans have the highest rates of any racial/ethnic group for several forms of cancer including liver, uterine, cervical, and stomach cancers (Miller et al., 1996).

More specifically, the incidence rate of liver cancer for some Asian ethnic subgroups is 10 times that of non-Hispanic Whites, making liver cancer the most significant cancer disparity for Asian Americans (Euler, 2001; Nguyen et al., 2007). The National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) data from 1998 to 2002 showed that, among Asian men, Lao Americans

(including Hmong) had the highest incidence of liver cancer (79.4 per 100,000), followed by Vietnamese (55.5 per 100,000), Samoan (54.5 per 100,000), Cambodian (49.1 per 100,000), and Korean (35.9 per 100,000). In contrast, the incidence rate for non-Hispanic White men was 6.7 per 100,000 (Miller et al., 2008). Another study that looked at hepatocellular carcinoma disparities among Californians of Asian descent showed that Laotian-Hmong men had the lowest survival rate compared to other Asian ethnic groups and that this group was more likely to be diagnosed at later stages of cancer, with only 3% undergoing any type of medical treatment, such as surgery or liver transplant (Kwong, Stewart, Aoki, & Chen, 2010).

### Hepatitis B and Southeast Asians

Previous studies have examined incidence rates of HBV infection, knowledge and beliefs of HBV, and barriers to screening and vaccination among Asian Americans as an aggregate racial group (Custer et al., 2004; Hsu et al., 2007; Pulido, Alvarado, Berger, Nelson, & Todoroff, 2001; Wu, Lin, So, & Chang, 2007). However, categorizing Asians into one large group ignores the heterogeneity of ethnic subgroups within the Asian American population. The term Asian Americans refers to people living in the U.S. whose familial roots originate from the continent of Asia including, but not limited to, Asian Indian, Bangladeshi, Bhutanese, Burmese, Cambodian, Chinese, Filipino, Hmong, Indonesian, Japanese, Korean, Laotian, Malaysian, Mien, Nepalese, Pakistani, Sikh, Sri Lankan, Thai, and Vietnamese (Asian

American Network for Cancer Awareness and Training [AANCART], n.d.). Not only are Asian Americans culturally and linguistically different, their histories and experiences in the U.S. are also quite different and can impact their health status and health-seeking behavior.

Little information on hepatitis B and liver cancer among specific high-risk Asian American populations such as Southeast Asians or, more specifically, the Hmong exists. Few studies have examined hepatitis B infection, screening and vaccination behavior related to hepatitis B, or liver cancer specifically among the Hmong, Lao, or Mien (ethnic minority groups from Southeast Asia). A literature search found only a handful of studies on hepatitis B that focused on Hmong Americans or that included Hmong in their sample (Butler, Mills, Yang, & Chen, 2005; Gjerdingen & Lor, 1997; Hurie et al., 1992; Mills, Yang, & Riordan, 2005; Sworts & Riccitelli, 1997; Vryheid, 2001). Three HBV or liver cancer studies included Laotians (Kwong et al., 2010; Miller et al., 2008; Sworts & Riccitelli, 1997), and no studies included the Mien. Although research is limited, studies have been conducted specifically with Vietnamese Americans (Burke, Jackson, Thai, Lam, et al., 2004; Burke, Jackson, Thai, Stackhouse et al., 2004; Choe et al., 2006; Hwang, Huang, & Yi, 2008; Jenkins, Buu, Berger, & Son, 2001; Ma, Fang, Shive, Toubbeh, Tan, & Siu, 2007; Ma, Shive, Fang, Feng, Parameswaran, Pham et al., 2007; McPhee et al., 2003; Taylor et al., 2005; Taylor et al., 2000) and Cambodian Americans (Hsu et al., 2007; Jenkins et al., 2001; Taylor, Jackson, Chan, Kuniyuki, & Yasui, 2002; Taylor, Seng, Acorda, Sawn, & Li, 2009) around hepatitis B knowledge, screening,

and vaccination behaviors. Other studies aggregate Southeast Asians as a general racial/ethnic category (Lin, Chang, & So, 2007; Mahoney et al., 1995). These studies show that Southeast Asians are at a particularly high risk for HBV infection and emphasize the serious consequences of not getting screened and vaccinated for HBV, as well as the need to develop culturally appropriate HBV prevention programs for this population. Furthermore, one study examining SEER data from 1998 to 2002 (Miller et al., 2008) found that liver cancer was among the top three cancers for Cambodians, Laotians, and Vietnamese men, and it was the fifth leading cancer incidence for Cambodian, Laotian, and Vietnamese women. As noted earlier, Kwong and colleagues (2010) found that, among Asians in California, Laotian-Hmong men experienced higher mortality rates compared to other Asian ethnic groups.

Moreover, little research has been done to shed light on knowledge and beliefs about HBV among the Hmong population or how cultural beliefs specifically influence knowledge and screening behavior. The existing research found that Southeast Asians (specifically Vietnamese, Cambodian, and/or Hmong) have low knowledge of risk factors for hepatitis B, transmission routes, and prevention methods (Burke et al., 2004; Butler et al., 2005; Gjerdingen & Lor, 1997; Hsu et al., 2007; Hurie et al., 1992; Ma et al., 2007; Mahoney et al., 1995; McPhee et al., 2003; Taylor et al., 2002, 2005). For example, Hsu et al.'s (2007) study of nine Asian American communities in Montgomery County, Maryland (MD) indicated that Southeast Asians had higher prevalence of HBV infection and lower knowledge of hepatitis B compared to other Asian ethnic groups. In a study with Cambodian women in Seattle,

Washington (WA) only 23% of participants knew that asymptomatic individuals can spread the disease to others, and 24% of participants were aware that HBV infection is a lifelong disease (Taylor et al., 2002).

As previously mentioned, horizontal transmission is a common mode of HBV transmission among Southeast Asians (CDC, 2006a; Gjerdingen & Lor, 1997; Hurie et al., 1992; WHO, 2010). Living in close proximity, having large family sizes, and having a high prevalence of HBV infection among family members are suggested risk factors for horizontal transmission of HBV among Hmong children (Gjerdingen & Lor, 1997; Hurie et al., 1992; Mahoney et al., 1995). Mahoney et al. (1995) found that Hmong children born to HBV negative mothers were more than five times more likely to have past HBV infection if they lived with an HBV carrier, compared to children who did not live with an HBV carrier. These researchers also found that the prevalence of chronic HBV infection increased with age. The studies mentioned above demonstrate that education and increased screening and vaccination is critical for the Hmong population, especially for parents whose children are susceptible to the HBV infection.

### Cultural Health Beliefs

Studies with various Southeast Asian groups have found other cultural and social factors identified as barriers related to hepatitis B and liver cancer knowledge and screening and vaccination behavior. Hurie and colleagues (1992), in their study

on the Hmong, suggest that traditional healing practices such as coin rubbing, pinching, or pricking the fingertips with sewing needles, may be contributing factors to horizontal transmission of HBV infection in this group. Skepticism about research may also be a contributing factor to screening and vaccination behavior. Gjerdingen and Lor's (1997) study showed that having participants sign a consent form was a major deterrent for participation in their study on hepatitis B status of Hmong patients. Other studies have shown that mistrust of authoritative figures, such as government officials and medical providers, may be embedded in Southeast Asians' historical experiences (Burke et al., 2004; Smith, 1997; Waters, Rao, & Petracchi, 1992). The kinds of misconceptions that may exist and the influence they have on individuals' hepatitis B and liver cancer knowledge and screening behavior deserve further investigation.

### Screening and Vaccination Behavior

In addition to the lack of knowledge about HBV, studies have also shown that screening and vaccination rates are low among Southeast Asians. A cross-sectional study of Asians in the San Francisco Bay area of California (CA) showed that only 12% of study participants reported having ever been vaccinated for HBV (Lin et al., 2007). Ma, Shive et al. (2007) reported, in their study among Vietnamese in the greater Philadelphia, Pennsylvania (PA) and New Jersey area, that a majority of study participants had never been screened (93%) or vaccinated (94%). Taylor and



colleagues' (2002) study on hepatitis B knowledge and practices among Cambodians in Seattle, WA found that only 38% ( $n = 123$ ) of study participants reported having ever been screened for HBV and, of those who had been screened, two-thirds had not been vaccinated.

Another important reason to further explore this health issue is that early detection can reduce the risk of dying from cancer; however, Asian American tend to be screened for cancer at lower rates compared to other racial and ethnic groups (ACS, 2005) and are diagnosed with cancer at later stages of the disease compared to their white counterparts (ACS, 2005; Kagawa-Singer & Pourat, 2000). Studies have shown that Asian American women are the least likely racial/ethnic group to obtain cervical cancer screening tests (Bird et al., 1998; Kagawa-Singer & Pourat, 2000; McPhee et al., 1997; Tanjasiri et al., 2001; Tosomeen, Marquez, Panser, & Kottke, 1996; Yi, 1994). Tanjasiri et al.'s (2001) study on Hmong women in California found that only 30% of women 40 years and older reported ever having a mammogram. Barriers that contribute to low cancer screening rates among Asian American women include lack of health insurance, length of time in the U.S., language and cultural barriers, low income, and lack of a usual source of care (Kagawa-Singer & Pourat, 2000; McPhee & Nguyen, 2000; McPhee et al., 1997; Pham & McPhee, 1992; Sadler, Nguyen, Doan, Au, & Thomas, 1998).

### Purpose and Significance of Study

HBV infection and liver cancer are significant health problems among the Hmong population and are largely preventable (Butler et al., 2005; Gjerdingen & Lor, 1997; Hurie et al., 1992; Miller et al., 2008). Knowledge and understanding of the factors that influence HBV infection screening and vaccination are limited. Furthermore, the Hmong have extremely high HBV infection rates and low hepatitis B screening and vaccination rates. The purpose of this study was to explore knowledge and beliefs about HBV infection and its transmission, as well as misconceptions of liver cancer, among the Hmong residing in Oregon. This exploratory study also examined perceptions of risks for HBV infection and barriers to hepatitis B screening and vaccination.

This study is significant in the following ways. First, little is known about this health problem (i.e., hepatitis B) among the Hmong, a population who emigrated from hepatitis B endemic geographical areas. There has been little research to shed light on the Hmong's knowledge and beliefs about the disease and their screening and vaccination behavior in relation to hepatitis B. The research is even more limited in terms of liver cancer in the Hmong population. The research findings will further inform scientific knowledge and future research with the Hmong on the health topics of hepatitis B and liver cancer. Furthermore, the literature shows that data on hepatitis B and liver cancer among the Hmong in Oregon do not exist; therefore, this would be the first exploratory study to examine this health issue in this specific population. Finally, understanding Hmong beliefs about HBV infection and liver cancer are

important for the development of culturally tailored hepatitis B and liver cancer information and for interventions to increase screening and vaccination rates in this population.

## CHAPTER 2. LITERATURE REVIEW

This chapter begins with a detailed description of hepatitis B and the adverse health consequences of HBV infection. Next, a review of the literature on HBV infection in the Hmong and other Southeast Asian populations and a description of the cultural, social, and historical background of Hmong immigrants are presented. Research on hepatitis B specifically targeting the Hmong population is limited; therefore, hepatitis B research with other Asian, specifically Southeast Asian ethnic groups, are also included in the literature review. Traditional health beliefs, medical decision-making, and barriers to hepatitis B screening and vaccination among the Hmong and other Southeast Asians are presented in the next section. A discussion of the theoretical framework for the study, including the ecological perspective, the Health Belief Model (HBM), and the Explanatory Models Approach follows. Finally, the research questions and hypotheses are presented.

### Hepatitis B

The hepatitis B virus belongs to the family of hepadnaviruses and it causes HBV infection (Lok & McMahon, 2001). Once the hepatitis B virus enters the body via the bloodstream, it travels to the liver where it replicates itself. The hepatitis B virus causes both acute and chronic hepatitis B infections. Acute HBV infection refers to the short-term, initial stage of infection, which normally lasts two to four months,

but no more than six months (CDC, 2005). According to the CDC (2006b), most adults who are newly infected experience few or no noticeable symptoms, and infants and children aged five and younger are usually asymptomatic. Still, some adults will experience symptoms of acute hepatitis B such as jaundice (yellowing of the skin and whites of eyes), fatigue, loss of appetite, weight loss, abdominal pain, fever, nausea, diarrhea, vomiting, and dark urine and/or pale stool (CDC, 2006b). Other symptoms such as skin rashes, arthralgias (joint pain), and arthritis can also occur. If symptoms do occur, they usually appear within two to three months after exposure to the hepatitis B virus and can last anywhere from two weeks to several months (CDC, 2006b). During acute infection (or within the first six months of infection), an individual can transmit the hepatitis B virus to others whether or not symptoms are present (CDC, 2006b). The fatality rate for severe cases of acute HBV infection is 0.5% to 1%, with the highest rate among people aged 60 years and older (CDC, 2006b).

According to the CDC (2006b), an estimated 95% of infected adults will usually clear the newly acquired HBV infection and become immune to the virus. Infants, young children, and immunosuppressed persons (e.g., individuals with a weakened immune system or those undergoing dialysis or chemotherapy) are at the greatest risk for developing chronic infections. Chronic HBV or long-term infection refers to an infection that lasts more than six months. Without proper treatment, infants who are infected at birth have more than a 90% risk of developing chronic infection (CDC, 2008c). HBV infection becomes chronic in approximately 25% to

50% of children aged one to five years, and in up to 5% of older children and adults (CDC, 2008c). The CDC (2008c) states that persons with chronic infections may be asymptomatic for several years before showing any signs of infection and if symptoms do occur, they are similar to those of acute infection.

### Adverse Health Consequences

Approximately 25% of individuals with chronic hepatitis B infections develop progressive liver disease, including cirrhosis, liver cancer, and liver failure (CDC, 2006b). Liver cancer often develops between the ages of 35 to 65 years and is more common in men than in women (ACS, 2007). Hepatitis B infection is often called a “silent killer” because an infected person may go for several years without showing any signs of illness. Chronic hepatitis B infection is one of the primary causes of liver cancer (ACS, 2007). The American Cancer Society (2011) states that there is a slow rise in liver cancer rates in the U.S. and estimated that 24,120 new cases of primary liver cancer and intrahepatic bile duct (tubes that carry bile to the gallbladder within the liver) cancer were diagnosed and approximately 18,910 people died of these cancers in the U.S. in 2010.

According to the Asian Liver Center (2007), Asians who are chronically infected with the HBV can develop liver cancer as early as their teenage years if they were infected at birth or early childhood. Symptoms often do not show until advanced stages of the disease; therefore, liver cancer can be extremely difficult to diagnose

early and treat (Asian Liver Center, 2007). If cancer tumors are found in the early stages of the disease, they can be surgically removed (Asian Liver Cancer, 2007). The 5-year survival rate from early stage of liver cancer is 30% to 60% and decreases significantly ( $< 5\%$ ) for people with advanced stages of liver cancer (ACS, 2007). The overall 5-year survival rate for liver cancer patients is less than 10% (ACS, 2007). The Asian Liver Center (2007) recommends that, for long-term survival, individuals with chronic hepatitis B should receive regular liver cancer screenings involving both alpha-fetoprotein and ultrasound tests.

### Hepatitis B Screening and Vaccination Recommendations

There is no cure for hepatitis B, but it is highly preventable. Screening is an important first step in preventing HBV infections. Because many chronically infected individuals may show no signs and symptoms of HBV infection, screening is important to identify persons who are infected and vaccinate those who may be susceptible (e.g., family members, sex partners), thereby preventing ongoing disease transmission (CDC, 2008c). The CDC (2008c) recommends routine hepatitis B screening for the following populations: 1) persons born in geographic regions with HBsAg (hepatitis B surface antigen, which indicates infection with HBV) prevalence of  $\geq 2\%$  (e.g., Asia, Pacific Islands, Africa, the Middle East, and much of Eastern Europe); 2) U.S.-born individuals not vaccinated as infants whose parents were born in geographic regions with high HBsAg prevalence of  $\geq 8\%$ ; 3) person with behavioral

exposures to HBV, such as injection drug users (IDU) and men who have sex with men (MSM); 4) persons receiving immunosuppressive therapy (e.g., chemotherapy); 5) persons with liver disease of unknown etiology; 6) donors of blood, plasma, organs, tissues, or semen; 7) hemodialysis patients; 8) pregnant women; 9) infants born to HBsAg positive mothers; 10) persons who are in occupations in which they are at increased risk for HBV exposure, such as health care and public safety workers; and 11) HIV-infected persons.

Hepatitis B infection is also preventable through vaccination. The hepatitis B vaccination is one of two vaccinations (the other is the hepatitis A vaccination) available to protect individuals from viral hepatitis infections. The hepatitis B vaccination is a three-shot vaccination series to be administered at zero, one, and six months, and it does not require a booster shot (CDC, 2006c). The CDC (2005) recommends that infants receive the hepatitis B vaccination soon after birth. For healthy adults (aged  $\leq 40$  years), approximately 30% to 50% develop a protective antibody response after the first dose, 75% after the second dose, and more than 90% after the third dose (CDC, 2006c). Addressing the hepatitis B immunization problem among U.S. adults and children is a major goal of the federal government. Healthy People 2010 listed among its myriad objectives 1) the reduction of chronic HBV infections in infants and young children and 2) the reduction of hepatitis B in adults and high-risk groups (U.S. Department of Health and Human Services, 2001). These goals were set to increase hepatitis B vaccination coverage among infants, children, and adults. Furthermore, in regard to hepatitis B vaccination, the CDC (2005, 2006b)



recommends that: 1) all pregnant women be tested routinely for HBsAG; 2) infants born to HBsAG positive mothers receive hepatitis B vaccine and hepatitis B immune globulin (HBIG) within less than 12 hours of birth; 3) all infants be universally vaccinated against the HBV; 4) children and adolescents who were not previously vaccinated be vaccinated against the HBV; and 5) unvaccinated adults at increased risk for infection (e.g., MSMs, IDUs, health care and public safety workers with risk for exposure to blood or blood contaminated body fluids, and hemodialysis patients) be vaccinated.

There is no specific treatment for acute HBV infection symptoms. However, treatment and disease management differs for people with chronic HBV. Among persons with chronic HBV infection, the risk for premature death from cirrhosis and liver cancer is 15% to 25%, thus the CDC (2008c) recommends that chronic HBV infected persons should be evaluated immediately after diagnosis by a physician who is knowledgeable and experienced in chronic liver disease management. Chronic HBV infected persons will have to be monitored for the rest of their lives to assess for liver disease progression, development of liver cancer, need for treatment, and response to treatment (CDC, 2008c). Furthermore, hepatitis B disease management and treatment depends on several factors, including family history, age, and condition of patient. Medical therapies to treat HBV are beyond the scope of the proposed study and will not be discussed.

In summary, HBV infection is highly preventable through vaccination. Because infected individuals are often unaware of their infection status, screening is

an important step to identify infected individuals in order to prevent transmission to others who are uninfected. Screening and vaccination is particularly important for the Hmong population, as they are from geographic areas where HBV infection is endemic. A discussion of HBV infection among the Hmong follows.

### Hepatitis B among the Hmong Population

Although the hepatitis C virus is the most common cause of liver cancer in the U.S., hepatitis B is the most common cause of liver cancer in Asia (with the exception of Japan, where hepatitis C is more common than hepatitis B) and other developing countries (ACS, 2007; Tsukuma, Tanaka, Ajiki, & Oshima, 2005). Hepatitis B is endemic to almost all of Asia, specifically China and Southeast Asia, making an examination of the knowledge of hepatitis B and barriers to screening and vaccination for populations emigrating from Asian countries particularly important. For example, in Asia, 8% to 10% of the adult population is chronically infected with hepatitis B, compared to less than 1% of the adult population in Western Europe and North America (WHO, 2008).

Of the few hepatitis B studies that have included the Hmong, results show that the prevalence of HBV infection is high, yet knowledge of HBV infection is low (Butler et al., 2005; Gjerdingen & Lor, 1997; Hurie et al., 1992; Vryheid, 2001). For example, in Butler et al.'s (2005) study with a small sample of Hmong youth in Fresno, California on hepatitis B knowledge and liver cancer ( $n = 65$ ), only 50% of

youth aged 15-18 years and 49% of adolescents aged 19-25 years knew that HBV could be spread through sexual intercourse. Although they found that knowledge of vaccination to prevent HBV infection was high in both age groups, the prevalence of HBV vaccination was low for both (20% among 15-18 year olds and 16% among 19-25 year olds). In another study with Hmong in St. Paul, Minnesota where researchers viewed clinical records of 434 patients (Hurie et al., 1992), results showed that 18% had acute or chronic HBV infection. Of those with HBV infection, 28% were among youth 15-19 years old.

### The Hmong in Oregon

Similar to national trends, the Asian American population in Oregon is growing rapidly. The U.S. Census estimated that Oregon's Asian population made up 3.7% (127,339 Asian alone and in combination with one or more races) of Oregon's total population in 2000. More recent data from the 2010 U.S. Census estimated that Oregon's Asian population (Asian alone category) had increased by 39.4% to 3.7% of the state's total population (3,831,074) (U.S. Census, n.d.). Oregon's Asian population is composed of both refugees and immigrants, with the vast majority of the Southeast Asian refugee population arriving in Oregon in the years following 1975. Of the entire Asian population in Oregon, Vietnamese is the second largest Asian group, followed by "other Asians" which is the subgroup that includes all other Southeast Asians (e.g., Hmong, Mien, Cambodia, Lao) (U.S. Census, 2000).

Several reasons exist concerning the importance of studying HBV infection among the Hmong living in Oregon. First, there has been a substantial increase in Oregon's Hmong population size. The Hmong population increased considerably from 1990 to 2000 from a population of 438 to 2,101 (Association of Asian Pacific Community Health Organizations [AAPCHO], 2004). Data from the 2010 U.S. Census for Hmong in Oregon was not available at the time of this study; however, Hmong community estimates that there are approximately 3600 Hmong residing in Oregon as of 2009. Another reason to examine the Hmong population in regards to hepatitis B is that this population comes from geographical areas where HBV is endemic (e.g., Laos, Thailand) and many Hmong are the first generation of their families in the U.S. Although data on foreign-born Hmong in Oregon are not available, according to the U.S. Census (2000), an estimated 8.5% (or 289,702) of Oregon's population was born outside of the U.S. Of those foreign-born individuals, 27.3% (79,183) were from Asia (U.S. Census, 2000) where hepatitis B is endemic. In addition, the Oregon Department of Human Services reported the cases of chronic hepatitis B in 2005 were higher among Asian Oregonians (148 cases) compared to other racial/ethnic groups (16 cases for blacks, 8 cases for American Indian/Alaska Native, 2 cases for Pacific Islander, 114 for whites, and 12 for Hispanic) (Oregon Department of Human Services [DHS], 2008). Furthermore, to date no studies have examined hepatitis B screening and vaccination behavior for Hmong in Oregon. In order to better address HBV infection among Hmong and increase their hepatitis B immunization rate, cultural, social, and institutional barriers to screening and

vaccination must first be explored. A more detailed examination of the Hmong's historical experiences, health beliefs and practices, and barriers to screening follows.

### Hmong Historical and Sociocultural Background

The Hmong have been arriving in the U.S for more than three decades. They were a part of the mass migration movement of millions of refugees known as *Indochinese refugees* (from here on referred to as Southeast Asian refugees) who, at the end of the Vietnam War in 1975, fled from the mainland Southeast Asian countries of Cambodia, Laos, and Vietnam and sought asylum in other parts of the world (Hein, 1995).

The Hmong have a long history of migration and persecution. In the 17<sup>th</sup> century, western missionaries first came into contact with the Hmong in China (Quincy, 1988). As a result of their resistance to acculturation, the Hmong were often victims of slavery, genocide, and oppression (Livo & Cha, 1991). Many Hmong fled to neighboring Laos, Thailand, Vietnam, and Burma, where they settled in the mountainous regions of those countries and were left in seclusion until the 1950s (Smith, 1997).

Most of the Hmong living in the U.S. emigrated from Laos. The Hmong may be best known for their participation in the Secret War in Laos (Hamilton-Merritt, 1993). In 1961, the Hmong were recruited by the U.S. Central Intelligence Agency to be a part of their "secret army" to fight the Communist Pathet Lao government. In

exchange for their military commitment, the U.S. offered the Hmong protection and transportation out of the country if the U.S. were to withdraw from the Vietnam War. When the U.S. withdrew its troops from Southeast Asia in 1975, thousands of Hmong allies were left behind to face persecution from the Lao communist forces. An estimated 40,000 to 50,000 Hmong fled from Xieng Kouang, the province where most of the battles during the Secret War in Laos took place (Duchon, 1997). Thousands died in battle and flight, while others made it to Thailand and were placed in refugee camps. Nations throughout the world, such as France, Australia, and the U.S., sponsored approximately 1.5 million Southeast Asian refugees, with the U.S. taking in the largest number (Hein, 1995). From 1975 to 2005, more than 1.3 million Southeast Asian refugees resettled in the U.S. (Office of Refugee Resettlement [ORR], 2005). Of the 1.3 million, more than 130,000 were Hmong (Congressional Research Service [CRS] Report for Congress, 2008). In 2004, another 15,000 Hmong refugees from the Wat Tham Krabok encampment in Northern Thailand were resettled in the U.S. (U.S. Department of State Bureau of Population, Refugees, and Migration, 2004). As of 2000, more than 184,000 Hmong live in the U.S., with the largest communities in California, Minnesota, Wisconsin, and North Carolina (SEARAC, n.d; U.S. Census, 2004).

## Health Beliefs and Practices

### *Beliefs about Illness*

The Hmong have different concepts of health, illness, healing, and treatment than Westerners (Chung & Lin, 1994; Her & Culhane-Pera, 2004; Parker & Kiatoukaysy, 1999). Traditional Hmong beliefs about illness and well-being are based primarily on animism (a belief that all natural objects and individuals have souls), ancestral worship, and soul calling (Bliatout, 1982; CDC, 2008b). Furthermore, health beliefs and practices are often interconnected with spiritual and religious beliefs (Bliatout, 1982). Some illnesses are believed to be caused by evil spirits, soul loss, or offended spirits (Bliatout, 1982). The Hmong believe that a person has multiple souls and one of the souls being lost or frightened away can cause an individual to become ill (Bliatout, 1982). They also believe that illnesses can occur due to the imbalance of metaphysical forces of hot and cold (Aronson, 1987; Burke, Jackson, Thai, Lam, et al., 2004; Burke, Jackson, Thai, Lam, Stackhouse, et al., 2004; Kemp, 1985; Landrine & Klonoff, 2001; Ong, Back, Lu, Shakespeare, & Wynne, 2002). The Taoist concept of balancing hot (yang) and cold (yin) ensures that the body remains in a healthy state to stave off illness and disease (Aronson, 1987; Burke, Jackson, Thai, Lam, et al., 2004; Burke, Jackson, Thai, Lam, Stackhouse, et al., 2004; Cha, 2003; Ong et al., 2002). An imbalance of these forces may lead to illness or disease, it is thought.

The concept of fatalism is a belief held by the Hmong. The idea of fatalism involves the notion that all events are predetermined by fate. The experience of war and trauma among the Hmong may perpetuate these fatalistic ideals (National

Diabetes Education Program [NDEP], 2006). According to the NDEP (2006), during the Vietnam War, Southeast Asian refugees experienced traumatizing events in which they had no control over their lives and they did not know what would happen to them and their families or where they would end up. These fatalistic beliefs persist, creating barriers to health care. The belief in fatalism is often found to be a barrier to cancer screening among the Hmong and other Southeast Asians (Burke, Jackson, Thai, Lam, et al., 2004; Kemp, 1985; Ong et al., 2002; Pham & McPhee, 1992; Sadler et al., 1998). Cancer is often perceived to mean death in Hmong culture, and the Hmong believe that even thinking about cancer could provoke the onset of the disease (Burke, Jackson, Thai, Lam, et al., 2004; Sadler et al., 1998). Burke and colleagues (2004) found, in their study on cervical cancer and Vietnamese women, that participants avoided talking about Pap tests because they did not want to find out if they had cancer, and that having cancer is a fate that they cannot change, so they preferred not to know. In fact, Pham and McPhee (1992) found that the perception that little can be done to prevent cancer might cause individuals to be unwilling to seek preventive care, in particular cancer screening.

### *Traditional Healing Methods*

Traditionally, Hmong practice self-medication for various illnesses, often using medicinal herbs and remedies, dermal techniques, observing a balance between hot and cold (e.g., avoiding certain foods when ill or in a certain state, such as post-partum), and spiritual healing (CDC, 2008b). Selection of the specific type of



treatment to use depends on the nature of the illness (Aronson, 1987; Cha, 2003).

Individuals such as shamans, herbalists, and magical healers who can diagnose and treat ailments often carry out the traditional healing practices mentioned above.

Traditional healers can treat symptoms that are of natural causes (e.g., nausea, headaches, and fevers) or of supernatural causes (e.g., soul loss, curses). Shamans are common spiritual healers in the Hmong culture. Hmong shamans (*txiv neeb*) do not choose to become shamans, but rather are chosen by ancestor spirits (Bliatout, 1982). The Hmong believe that shamans can travel between the physical and spiritual world to cure illnesses by bringing back an individual's soul or by appeasing offended spirits (Bliatout, 1982; Cha, 2003). Researchers note that, as Hmong convert to Christianity, the use of shamans is no longer practiced because the worship of ancestor spirits goes against Christian beliefs (Cha, 2003; Culhane-Pera & Xiong, 2003).

Other types of traditional healing practices in Hmong culture include dermal techniques such as cupping, pinching or rubbing, coining, spooning, acupuncture, therapeutic burning, and massage. These techniques are used to relieve symptoms such as headaches, joint and muscle pains, fevers, diarrhea, colds, coughs, and other physical symptoms (Cha, 2003; Culhane-Pera & Xiong, 2003). The Hmong believe that these dermal practices are used to release excess wind or internal heat due to stress or internal energy imbalance that, in turn, can cause illness (Cha, 2003). A family member or a trained healer normally performs dermal therapies and, if they are not successful in curing the individual, then a folk healer (e.g., shaman) is sought (Culhane-Pera & Xiong, 2003).

*Attitudes toward Western Medicine*

For many Southeast Asian immigrants, the Western health care system is used either in combination with traditional healing practices or as a last resort if traditional practices do not work (Aronson, 1987; Cha, 2003; Gilman, Justice, Saepharn, & Charles, 1992; Uba, 1992). However, the Hmong are less familiar with the use of biomedicine and adherence to biomedical treatment and are the least likely, compared to other Asian Pacific Islander ethnic groups, to utilize Western health care services (Chung & Lin, 1994). Treatment prescribed by medical doctors often requires invasive procedures or medical regimens that are not compatible with traditional Hmong health beliefs and practices. As a result, Hmong patients are often resistant toward invasive procedures, in particular surgical procedures (Her & Culhane-Pera, 2004; Johnson, 2002; Parker & Kiatoukaysy, 1999). The Hmong believe that the removal of body parts will interfere with reincarnation in the next life. Other Southeast Asian ethnic groups also experience fear of surgical procedures. For example, in Burke and colleagues' (2004) study on cervical cancer among Vietnamese women, found that the women in their study feared surgery, believing that surgery would cause the cancer to spread or leave them infertile and less valuable to their husbands.

Some of these fears and resistance toward Western medicine may stem from unfamiliarity with the anatomy of the human body and its organ functions (Johnson, 2002), as well as the lack of knowledge about Western medicine and its health care

system (Kemp, 1985). For example, Hmong patients are reluctant to have their blood drawn or have blood transfusions due to the belief that blood is their life force and having too much blood drawn may either cause the patient's spirit to leave the body or cause death (Johnson, 2002; Parker & Kiatoukaysy, 1999; Rairdan & Higgs, 1992). According to Waters and colleagues (1992), Hmong in Laos had very little contact with Western physicians, which may have contributed to their mistrust of the Western medical system. The vast majority (80-90%) of Hmong refugees in Laos had never been seen by a physician (Smith, 1997). Waters et al. (1992) state that many physicians in Laos had inadequate training. In addition, access to health care was limited, and medical facilities were poorly equipped. Because the Hmong had limited exposure to and understanding of Western medicine, many believed that Lao medical students were experimenting on them (Waters et al., 1992). Those who did seek Western medical care, only after traditional healing methods failed, were often already quite ill. As a result, outcomes were either poor or even fatal. Hospitalization came to be viewed as a place to go before death. Many Hmong, today, still fear hospitals (Smith, 1997). Furthermore, Western medicine often conflicts with Hmong health beliefs and practices and, thus, further strengthens Hmong people's mistrust of physicians and hospitals in the U.S. (Parker & Kiatoukaysy, 1999). Moreover, due to the Hmong's political history with various governments, Hmong immigrants often worry about using free health care programs for fear that it may negatively affect their residency status or use of other government resources, such as welfare benefits (Yu et al., 2002). Tanjasiri et al. (2002) found that Hmong women were reluctant to

participate in their study on breast cancer due to fear that revealing personal information would put their welfare status at risk.

### *Medical Decision-making*

In most Asian cultures, particularly the Hmong, the notion of collectivism is strongly emphasized, in which actions are conducted and decisions are made for the good of the group rather than for the good of the individual (Her & Culhane-Pera, 2004; Johnson, 2002; Landrine & Klonoff, 2001; Ong et al.; 2002). In regards to medical decision-making, the approach in Hmong culture is a family-centered model of decision-making, rather than the patient autonomy model that is common in Western societies (Her & Culhane-Pera, 2004; Johnson, 2002). The Hmong's kinship-based society places tremendous emphasis on lineage and clan ties for security and mutual assistance (Dunnigan & Olney, 1985; Finck, 1981). The Hmong kinship system is patrilineal and made up of 23 clans. Clan membership can usually be distinguished by surname. Because Hmong is a kinship-based culture that values family decision-making, medical decision-making is a communal act rather than an individual act (Her et al., 2004; Johnson, 2002). For example, medical decisions relating to other immediate family members are usually left up to the male head of household (i.e., the husband or eldest son) (Cha, 2003; Her & Culhane-Pera, 2004; Johnson, 2002; Parker & Kiatoukaysy, 1999). As a collectivist culture, a Hmong person's identity should be reflective of the larger group, such as his/her family or clan, because decisions will ultimately have an effect on the group (Her & Culhane-

Pera, 2004; Johnson, 2002). Patients may also seek consultation from extended family members and/or clan leaders before making a medical decision. In medical crises, family members may travel long distances to consult other family members.

According to Johnson (2002), Hmong women generally do not have the autonomy to make important medical decisions for themselves; their husbands must be consulted before final medical decisions are made.

Traditional health and healing practices continue to persist among the Hmong living in the U.S. and may pose potential barriers to hepatitis B and liver cancer knowledge, attitudes, and beliefs (Butler et al., 2005; Cha, 2003; Gjerdingen & Lor, 1997; Pham & McPhee, 1992) and warrants further investigation. Screening and vaccination behavior also warrants further exploration because hepatitis B screening and vaccination rates are markedly low (Butler et al., 2005; Gjerdingen & Lor, 1997; Hurie et al., 1992). A discussion about the barriers to screening is presented below.

### Barriers to Health Screenings

A review of the literature shows that Hmong experience numerous barriers to accessing health care, particularly preventive health screenings (e.g., Pap tests, mammograms), including but not limited to economic, educational, cultural, social, acculturation, and language barriers (Gilman, 1992; Ghosh, 2003; Tanjasiri et al., 2001). In this section, a discussion of the barriers to both hepatitis B and cancer

screenings faced by Asians in general, as well as Hmong, specifically, will be presented.

### *The Model Minority Myth and Health Disparities*

The notion that Asian and Pacific Islanders (API) are the “good” minorities that work hard and never complain and the minority group that other minority groups should emulate best summarizes the model minority myth, a racial stereotype that has been applied to APIs since the 1960s (National Commission on Asian American and Pacific Islander Research in Education [CARE], 2008; Wu, 2002). This idea that APIs, in general, do well, excel academically, and are economically successful is an unrealistic and unfair representation of all APIs. According to the model minority myth, APIs, as a group, are “intelligent, gifted in math and science, polite, hard working, family oriented, law abiding, and successful entrepreneurial” (Wu, 2002, p. 49). The model minority myth implies that the success of Asians in the U.S. is a standard that all minorities should live up to (Wu, 2002). This creates unrealistic expectations, not just for Asians who do not do well, but also suggests that other minorities be compared to this stereotype of Asians. Furthermore, the model minority myth suggests that Asians are a homogenous group; however, the reality is that there is extraordinary diversity within and among this population. According to Wu (2002), the model minority myth should be rejected for the following reasons:

“1) The myth is a gross simplification that is not accurate enough to be seriously used for understanding 10 million people, 2) it conceals within it an invidious statement about African Americans along the lines of the

inflammatory taught: ‘they made it; why can’t you?’ and 3) the myth is abused both to deny that Asian Americans experience racial discrimination and to turn Asian Americans into a racial threat” (p. 49).

The erroneous belief that APIs are a healthy population is a perception that many APIs, themselves, and policy makers tend to have of APIs (Kagawa-Singer & Pourat, 2000). In reality, there are marked disparities across API ethnic groups. Many struggle with poverty, English language proficiency, low wage jobs, and lack of health care coverage, which may lead to poorer health status than other racial and ethnic groups (Ponce et al., 2009). For example, in a study summarizing cancer incidence for five of the largest Asian American ethnic groups in California, Miller and colleagues (2008) found that Filipino men have the highest incidence and mortality rates for prostate cancer among all Asian ethnic groups, while Korean Americans had the highest rate of stomach cancer compared to the other Asian ethnic groups.

When health outcomes of Asian Americans are compared to whites, the differences are even greater. For example, cervical cancer is five times higher among Vietnamese women compared to white women (Miller et al., 1996). Although cancer rates among Asians as a group are low compared to whites, cancer is the number one cause of death among Asian and Pacific Islander women (Chen & Koh, 1997; Office of Minority Health & Health Disparities [OMHD], 2010). Furthermore, cancer screening rates are the lowest among APIs compared to other ethnic groups (ACS, 1998), a partial result of the traditional health beliefs discussed above. Another example is the smoking rate for Asian Americans. In general, Asian American adults have the lowest smoking prevalence rates (10.3%) compared with other racial and

ethnic groups, a rate that is much lower than that for American Indians/Alaskan Natives (32.2%), non-Hispanic whites (21.8%), non-Hispanic blacks (22.6%), and Hispanics (15.1%) (American Lung Association [ALA], 2008); however, if the data is disaggregated, current smoking rates vary among Asian ethnic subgroups and are substantially higher for some Southeast Asian ethnic groups compared to other racial and ethnic groups. For example, current smoking rates for Vietnamese males ranges between 35% and 56% (Moeschberger et al., 1997; Wiecha, Lee, & Hodgkins, 1998), for Cambodian males between 35% and 55% (Moeschberger et al., 1997), for Laotian between 47% and 72% (Levin, Nachampassach, & Xiong, 1988); and for Korean 39% (Moeschberger et al., 1997).

### *Language*

The ability to speak and read English has a profound impact on access to health care and health information, communication with medical personnel, and the ability to understand and properly follow medication instructions (Asian and Pacific Islander American Health Forum [APIAHF], 2006; Ngo-Metzger, 2007). In 2000, the U.S. Census (2003a) reported that approximately 18% (47 million) of the total U.S. population aged five and over spoke a language other than English at home and, of those 47 million people, 22% reported speaking English less than “very well.” Among the 9.5 million Asians aged five and over, 79% spoke a language other than English at home and approximately 40% spoke English less than “very well” (U.S. Census, 2004). Southeast Asian subgroups such as Cambodians, Hmong, Laotians,



and Vietnamese had the highest percentages of people who spoke a language other than English at home (over 90%), with the Vietnamese having the highest percentage of people who reported speaking English less than “very well” (62%) (U.S. Census, 2004). A study of APIs in California (Ponce et al., 2009) reported that 44% of Hmong had limited English proficiency compared to 36% of Asians as an aggregate group.

When seeking health care, individuals with limited English proficiency often report worse access to health care, poorer quality of care, and lower satisfaction with care compared to proficient English speakers (Derose, Escarce, & Lurie, 2007; Jacobs, Karavolos, Rathouz, Ferris, & Powell, 2005; Ngo-Metzger et al., 2007; Ponce, Hays, & Cunningham, 2006; Timmins, 2002). Individuals with limited English proficiency are also less likely to have health insurance, have a usual source of care, or receive preventive care, and they have fewer physician visits than those who speak English well (Derose et al., 2007; Ponce et al., 2006). Using interpreters and providing LEP individuals with access to medical providers who are bilingual and bicultural have been found to reduce language barriers for LEP individuals (Baker, Parker, Williams, Coates, & Pitkin, 1996; Flores, 2005; Perez-Stable, Napoles-Springer, & Miramontes, 1997).

For the Hmong, language barriers pose tremendous challenges when it comes to accessing health care. For example, English language proficiency is a huge barrier for older Hmong, especially in scheduling medical appointments, getting directions to hospitals or clinics, or dialing emergency services (Parker & Kiatoukaysy, 1999; Pinion-Perez, 2006; Tanjasiri et al., 2001; Yu et al., 2002; Yang et al., 2004).

Furthermore, many Western medical terminologies are nonexistent in the Hmong language (Parker & Kiatoukaysy, 1999). For example, no words exist in the Hmong language for “cancer,” “ultrasound,” or “mammography.” Literacy challenges for the Hmong, in both English and their native languages, are unique in that the written Hmong language was not developed until 1953 when Christian missionaries devised one for them (Dunnigan & Olney, 1985). This relatively newly written language is evolving and it is unclear how many Hmong use the written language or, as new generations acculturate to the U.S., how use of this language will change over time.

In regards to hepatitis B, studies show that language was a significant barrier to receipt of screening and vaccination (Coronado et al., 2007; Hwang et al., 2008; Kim & Telleen, 2001; Ma et al., 2007; Pulido et al., 2001). Pulido and colleagues (2001) found that Chinese parents who never spoke English at home were less likely to have their children’s hepatitis B vaccinations up-to-date compared to Chinese parents who spoke mostly English at home. Results from Coronado et al.’s (2007) study with Chinese Americans showed that respondents who needed a medical interpreter were less likely to receive a hepatitis B test compared to those who did not need an interpreter. Finally, Kim and Telleen (2001) found that Korean parents of children who were not up-to-date with their hepatitis immunization were more likely to report difficulty communicating (i.e., speaking English) at a physician’s office or health clinic as a perceived barrier to obtaining immunizations than parents of children who were up-to-date with their hepatitis immunization.

### *Acculturation*

Acculturation has been defined in various ways and extensively studied in public health. Redfield, Linton, and Herskovits (1936) define acculturation as the process of change that results from continuous firsthand contact between people from different cultures. Similarly, Berry (1986) conceptualizes acculturation as a process that occurs when people from differing cultural backgrounds come into contact with one another and an interchange of cultural attitudes and behaviors occur. Ma and colleagues (2004) define acculturation as a “process by which individuals or groups accept, selectively, aspects of another culture, often a dominant one, that those individuals or groups intend to adopt without completely relinquishing their own” (p.615).

The acculturation process can have tremendous impact on individuals’ beliefs, values, attitudes, and behaviors (Gordon, 1964). Acculturation has been shown to be associated with various health behaviors and health outcomes for immigrants (Anderson et al., 1993). For example, studies show that acculturation is associated with obesity and dietary behavior among Mexican American women (Balcazar, Castro, & Krull, 1995). Elders and colleagues (1991) found that less acculturated Mexican American women were more likely to have unhealthy dietary practices (i.e., less likely to avoid foods high in fat and more likely to consume high caloric foods) than more acculturated women, which in turn can lead to greater risk of being overweight (Elder et al., 1991 as cited in Balcazar et al., 1995). Studies also show that the level of acculturation is associated with certain health behaviors, such as smoking

(Fu et al., 2003; Ma et al., 2004; Marin et al., 1989 as cited in Ma et al., 2004). For example, among Asian American youth and women, higher levels of acculturation were associated with being a current smoker, whereas higher levels of acculturation had the opposite effect for Asian American men, that is, more acculturated Asian American men were less likely to smoke than less acculturated men (Ma et al., 2004).

Acculturation has also been shown to influence knowledge and attitudes that, in turn, affect health behaviors (e.g., cancer screenings, disease prevention behaviors) (Byrd, Peterson, Chavez, & Heckert, 2004; Choe et al., 2006; Hwang et al., 2008; Phipps, Cohen, Sorn, & Braitman, 1999; Yi, 1994). For example, Yi's study (1994) with Vietnamese women in Massachusetts found that the likelihood of obtaining a pap test was associated with greater length of residence in the U.S. Yi (1995) also found that more acculturated Vietnamese women were more likely to have private insurance and to have a regular source of care compared to less acculturated Vietnamese women. In regards to hepatitis B infection, Hwang and colleagues (2008) found that less acculturated Vietnamese college students in Texas were less likely to have been vaccinated for hepatitis B. In contrast, Choe and colleagues (2006) found that less acculturated Vietnamese men in Seattle, WA were more likely to have reported past hepatitis B screening. To the author's knowledge, there are no studies that examine acculturation in relation to hepatitis B among Hmong.

Acculturation is a complex and multifaceted process (Padilla, 1980). There are competing schools of thought on the nature of the acculturation process. The *unidimensional model* is described as a process whereby "individual acculturation is a

linear function of the amount of time a person has been exposed to the host culture, and the rate at which the acculturation process takes place is a function of the age and sex of the individual” (Szapocznik & Kurtines, 1980, p.141). In this model, acculturation takes a linear approach in that adaptation to the host culture causes an inevitable loss or weakening of one’s ethnic identity (Laroche, Kim, Hui, & Tomiuk, 1998; Park, 1928 as cited in Abraido-Lanza, Armbrister, Florez, & Aguirre, 2006). Other models suggest that acculturation occurs *bidimensionally*. The bidimensional model assesses acculturation to the native and host cultures along two independent dimensions (Szapocznik & Kurtines, 1980). According to Szapocznik and Kurtines (1980), “the first dimension consists of a linear process of accommodating to the host culture; the second dimension consists of a complex process of relinquishing or retaining the characteristics of the culture of origin” (p.144). In the bidimensional model, individuals retain their ethnic identity while acquiring characteristics necessary to participate in the host culture (Laroche et al., 1998). Other *multidimensional* models posit acculturation as a process based on cultural awareness and ethnic loyalty with dimensions, or factors, that play a role in determining acculturative change, such as language familiarity and usage, cultural heritage, ethnic pride and identity, and inter-ethnic interaction and inter-ethnic distance (Padilla, 1980).

To examine acculturation of Asian Americans, scales have been developed. Suinn, Rickard-Figueroa, Lew, and Vigil (1987) created the Suinn-Lew Asian Self-Identity Acculturation (SL-ASIA) Scale, a scale that is widely used to assess acculturation among Asians in the U.S. Critics of the SL-ASIA Scale state several

limitations of this scale: 1) the scale aggregates Asians into one ethnic category, 2) it does not assess a range of acculturation behaviors and situations, 3) it is based on a unidimensional model, and 4) the scale has been used with mostly Asian American students and/or faculty (Ponterotto, Baluch, & Carielli, 1998; Suinn et al., 1987).

Other scales include the Asian American Multidimensional Acculturation Scale (AAMAS) and the East Asian Acculturation Measure (EAAM). The AAMAS is based on the bidimensional model measuring acculturation to the host culture and Asian culture of origin (Chung, Kim, & Abreu, 2004). Other guiding principles of the AAMAS include the conception of a pan-ethnic Asian American culture and its ease of use across multiple Asian ethnic groups (Chung et al., 2004). The East Asian Acculturation Measure is based on Berry's (1986) four dimensions of acculturation – assimilation, separation, integration, and marginalization (Barry, 2001). The EAAM examines the acculturation patterns of mostly Chinese, Japanese, and Korean Americans. Furthermore, Anderson and colleagues (1993) developed a scale specifically for Southeast Asian immigrants and refugees (i.e., Vietnamese, Cambodian, and Laotian). Anderson and colleagues' acculturation scale was limited to only language proficiency and usage, and food preferences. Essentially, acculturation provides a conceptual bridge to understanding the relationship between immigration and changes in knowledge, attitudes, beliefs, and values which, in turn, influence health behaviors, including adoption of risky health behaviors (e.g., smoking) or preventive health behaviors (e.g., immunization). Thus, the impact of acculturation warrants further investigation.

### *Educational Attainment*

The heterogeneity of Asian Americans is evident in socioeconomic characteristics such as education and income. Education is commonly used as a measure of socioeconomic status (SES), as well as other variables, including income, occupation, and social status (Adler & Ostrove, 1999). It is well established that higher SES is associated with lower mortality rates and better health (Goldman, Kimbro, Turra, & Pebley, 2006). The differences in these characteristics between the Hmong, other Southeast Asian subgroups, and the majority population are discussed below.

Educational attainment varies tremendously between Asian American ethnic subgroups. According to the 2000 Census, Southeast Asian ethnic subgroups have two to 11 times more people with no formal education compared to Asian Americans as a whole and up to 32 times more than the general U.S. population (Vietnamese 8%, Laotian 22.7%, Cambodian 26.2%, and Hmong 45% versus Asian Americans 4.2% and U.S. population 1.4%) (Niedzwieki & Duong, 2004). The 2000 Census also reported that Southeast Asians are more than two to six times less likely to hold a bachelor's degree or higher compared to Asian Americans as an aggregate group and as much as three times less than the general U.S. population (Vietnamese 19.5%, Cambodian 9.1%, Laotian 7.6%, and Hmong 7.4% versus Asian Americans 42.7% and U.S. population 24.4%) (Niedzwieki & Duong, 2004). Ponce and colleagues' (2009) study on the state of Asian Americans', Native Hawaiians', and Pacific Islanders' health in California found that the Hmong population in that state had the

highest proportion of respondents with less than a high school education (48%) compared to all Asians (14%) and whites (8%).

Research shows that education is positively associated with health (Coburn & Pope, 1974; Feldman, Makuc, Kleinman, & Cornoni-Huntley, 1989; Ross & Wu, 1995). Educational attainment has been linked to several factors that affect health, directly and indirectly, such as the likelihood of having health insurance, greater satisfaction with overall health, and having a higher income. Among Asian Americans, studies show that low educational attainment is associated with not having a regular physician (Bird et al., 1998; McPhee et al., 1997). In relation to cancer prevention, education was a contributing factor to low knowledge of cancer and cancer screenings (i.e., breast and cervical cancer screening) among Cambodian and Vietnamese women (Phipps et al., 1999). In regards to hepatitis B, lower educational attainment is associated with lower knowledge of hepatitis B infection and screening and lower vaccination rates among Vietnamese Americans (Choe et al., 2006; Ma, Shive, et al., 2007).

### *Income and Poverty*

The association between income and health has also been well established. Studies show that higher income status is associated with having health insurance, more specifically, having private insurance versus having Medicare or Medicaid (Jang, Lee, & Woo, 1998). In turn, low-income status is associated with a lack of a usual source of health care, lack of health insurance, and dissatisfaction with medical



care (Shi & Stevens, 2005). Living in poverty and/or having a lower income can affect how individuals access health care and health information, and ultimately can affect one's health status. According to Ashing-Giwa and colleagues (2004), "lower SES women have difficulty keeping treatment and follow-up care due to transportation problems, work circumstances (inability to take time off, threat of job termination, loss of wages), or lack of childcare" (p. 72).

Economically, Asian Americans as a group may seem to do well or better than the general U.S. population in some areas, but a closer look reveals that income and poverty rates are markedly different when the data are disaggregated. According to the Census 2000 (U.S. Census, 2004), the median annual income for Asian American families was higher (\$59,324) than the median annual income for all U.S. families (\$50,046). However, it ranged dramatically from \$32,384 for Hmong families to \$70,849 for Japanese families in the U.S. Furthermore, Asian Americans as a whole have similar poverty rates as that of the total U.S. population (12.6% and 12.4%, respectively); however, the 2000 Census shows that poverty rates are significantly different for certain Asian ethnic subgroups. For example, Southeast Asians experience some of the highest poverty rates, with the Hmong having the highest individual poverty rates (37.8%), followed by Cambodians (29.3%), Laotians (18.5%), and Vietnamese (16%) (U.S. Census, 2004). In a study in California (Ponce et al., 2009), economic indicators for 2006 reported that the Hmong community, compared to the total California population, had the lowest per capita income (\$8,470 versus \$26,974), highest percentage of individuals living below poverty (approximately 32%

versus 13.1%), the highest unemployment rate (9.5% versus 4.2%), and the highest percentage of people who depended on public assistance (27.1% versus 3.2%) and food stamps (39.1% versus 4.3%).

### *Health Care Access*

Racial and ethnic disparities in access to health care have been extensively documented. A review of the literature by Mayberry, Mili, and Ofili (2000) revealed significant racial and ethnic differences in access to medical care within certain disease categories (e.g., heart disease and stroke, diabetes, cancer, infant and child health services, and mental health) and types of health services (e.g., use of preventive health services, visits to clinics, hospitals, and emergency rooms). For example, in regard to breast cancer screening, studies show that African American and white women had similar rates of mammography and clinical breast examinations, yet Hispanic women had much lower screening rates than both groups. In further examining the disparities in breast cancer, Mayberry and colleagues found that African American and Hispanic women were more likely to be diagnosed at advanced stages of cancer compared to white women. Mayberry and colleagues also state that insurance coverage and poverty status were significantly associated with medical care access. For example, in examining the literature on childhood immunization rates, several studies showed that low immunization rates among minority children were associated with insurance status and family characteristics. Furthermore, studies also documented that poor, non-white children experienced longer wait times and had

fewer visits at doctor's offices, and were more likely to use the emergency room for primary care (Mayberry et al., 2000). Mayberry and colleagues reviews of the literature included studies mostly comparing black and white health disparities and some studies included Hispanics, but other racial and ethnic minority groups such as Asians, Native Hawaiians/Pacific Islanders, Native Americans, and Alaska Natives were not reviewed or discussed due to the lack of data.

In specifically examining access to health care among Asian Americans and Pacific Islanders, a report produced by the Kaiser Family Foundation (2008) found large variation in the health care coverage among Asian Americans and Native Hawaiians and Pacific Islander (NHPI) populations. The Kaiser study revealed that non-elderly Asian Americans and NHPI were less likely to have employer-sponsored health coverage compared to non-Hispanic whites, and they are more likely to be uninsured. Uninsured rates ranged between 11% among Asians who had lived in the U.S. for three or more generations to 31% among Koreans. Reliance on Medicaid and other public coverage ranged from 4% among Asian Indians to 19% among other Southeast Asians (Kaiser Family Foundation, 2008). Native Hawaiians and Pacific Islanders are more likely to be uninsured and to be on Medicaid than both Asians and non-Hispanic whites (Kaiser Family Foundation, 2008). Having a usual source of care is a measure of access to care that is associated with use of preventive services and timely and appropriate medical care (Corbie-Smith, Flagg, Doyle, & O'Brien, 2002). The Kaiser study (2008) found that nonelderly Asian Americans and NHPI were more

likely to be without a usual source of care (18%) compared to non-Hispanic whites (14%).

In regards to hepatitis B, a study by Choe and colleagues (2006) with the Vietnamese population in Seattle, Washington found that Vietnamese men who had greater access to health care (that is, greater likelihood of having private health insurance, a regular health care provider, and short wait times at the doctor's office) were more likely to report having been tested for hepatitis B. In contrast, the Coronado and colleagues study (2007) with Chinese Americans in the same city (Seattle) found that health care access factors were not related to hepatitis B screening. Although the insurance rate among the study sample was fairly high (89%) and more than three quarters of the sample reported having a regular health care provider, less than half (48%) had ever been tested for hepatitis B. The findings in these two studies, as well as the other studies that have been mentioned in this section, indicate that there are likely to be multiple factors that influence hepatitis B screening and vaccination behaviors among Asian Americans and that these factors vary among Asian ethnic subgroups.

### Theoretical Framework

From previous research, it is known that knowledge alone does not enhance adoption of recommended screening behaviors. Accordingly, two widely used health behavior theories – the Ecological Perspective and the Health Belief Model (HBM) –

provide a theoretical framework for this study. The Ecological Perspective and the HBM have been used in previous research on hepatitis B with Asian Americans, specifically with other Southeast Asian populations (Hwang et al., 2008; Ma, Fang et al., 2007). In addition to the two health behavior models, the Explanatory Models Approach from the field of anthropology was used to guide the qualitative portion of this study. The theoretical framework is described further below.

### *Ecological Perspective*

It is well documented that health behaviors and health outcomes are influenced by multiple factors such as physical (e.g., neighborhood), social (e.g., economic), cultural (e.g., attitudes and beliefs), and biomedical (e.g., genetics) factors. The proposed research will draw from an ecological perspective to better understand Hmong medical decision-making around hepatitis B screening and vaccination. An ecological perspective to health promotion “emphasizes the interaction between, and interdependence of, factors within and across all levels of a health problem” (U.S. Health and Human Services, 2005, p.10). This theoretical perspective considers the reciprocal relationship of individuals and their environment. Proposed by McLeroy, Bibeau, Steckler, and Glanz (1988), the ecological perspective of health promotion emphasized that, in understanding health behavior, one should focus on the interactions of individuals on and by their social and physical environment. McLeroy and colleagues (1988) argue for the existence of multiple levels or factors that influence health behavior, including the *intrapersonal factors*, *interpersonal factors*,

*institutional factors, community factors, and public policy* (refer to Table 2.1 for definitions). The ecological perspective is an approach used to explore a particular health problem from varying and multiple perspectives. For example, receipt of hepatitis B screening and vaccination may be dependent on personal knowledge and attitudes about hepatitis B infection (intrapersonal). The decision to get screened and vaccinated may also be influenced by family (e.g., family member may be an HBV carrier) or friends (interpersonal), accessibility to low or no cost screening and vaccination clinics (institutional), existing community-wide hepatitis B prevention and education programs (community), and a mandatory immunization policy for work, school, or immigration purposes (public policy). The proposed research examines factors at the intrapersonal, interpersonal, and institutional levels that may affect hepatitis B screening and vaccination among Hmong.

Table 2.1  
*Ecological Perspective: Levels of Influence*

Concept	Definition
Intrapersonal Factors	Individual characteristics that influence behavior, such as knowledge, attitudes, and beliefs.
Interpersonal Factors	Interpersonal processes and primary groups, including family, friends, peers, that provide social identity, support, and role definition.
Institutional Factors	Rules, regulations, policies, and informal structures, which may constrain or promote recommended behaviors.
Community Factors	Social networks and norms, or standards, which exist as formal or informal among individuals, groups, and organizations.
Public Policy	Local, state, federal policies and laws that regulate or support healthy actions and practices for disease prevention, early detection, control, and management.

*Note.* From *Theory at a Glance: A guide for health promotion practice, second edition*, by U.S. Department of Health and Human Services, National Institutes of Health, & National Cancer Institute, NIH Publication No. 05-3896, 2005, Washington, DC: NIH.

### *The Health Belief Model*

Attitudes and beliefs that individuals hold about hepatitis B infection and liver cancer can act as barriers to screening, immunization, and treatment of the disease.

Theories, such as the Health Belief Model (HBM), help to explain how beliefs about hepatitis B and liver cancer and attitudes toward prevention measures influence individual screening and vaccination behavior (Hwang, 2008; Ma, Fang et al., 2007).

The HBM is widely used in studies to explain behavior change and as a theoretical framework for health behavior interventions (Janz, Champion, & Strecher, 2002).

This theory was first introduced in the 1950s by researchers at the U.S. Public Health Service examining why people would or would not participate in disease detection and

prevention programs (Rosenstock, 1966). According to the HBM, as explained by Janz et al. (2002), an individual will:

Take action to prevent, to screen for, or to control ill-health conditions if they regard themselves as susceptible to the condition, if they believe it would have potentially serious consequences, if they believe that a course of action available to them would be beneficial in reducing either their susceptibility to or the severity of the condition, and if they believe that the anticipated barriers to taking the action are outweighed by its benefits. (p. 47-48).

The theory is based on six core concepts: *perceived susceptibility* (an individual's belief regarding the chance of getting a condition), *perceived severity* (an individual's belief of how serious a condition and its sequelae are), *perceived benefits* (an individual's belief regarding the effectiveness of the recommended health behavior to reduce the disease threat), *perceived barriers* (an individual's belief about the tangible and psychological costs of the recommended health behavior), *cues to action* (factors that stimulate an individual to take action), and *self-efficacy* (the confidence in one's ability to perform the recommended health behavior) (Bandura, 1977; Janz et al., 2002).

### *Health Belief Model and Cancer and Hepatitis B Screening Studies*

The Health Belief Model has been used extensively to examine cancer screening behaviors, in particular beliefs, attitudes, and behaviors toward breast cancer screening (Aiken, West, Woodward, & Reno, 1994; Champion, 1984; Champion & Menon, 1997; Champion & Miller, 1996; Menon et al., 2007; Russell, Perkins,



Zollinger, & Champion, 2006; Yarbrough & Braden, 2001). Champion and colleagues have developed scales to measure HBM concepts of perceived risks, benefits, and barriers to breast cancer screening (Champion, 1984; Champion & Menon, 1997; Champion & Scott, 1997). Champion (1984) developed a scale to address breast self-examinations using constructs of the HBM. In more recent revisions of the scale, Champion and Menon (1997) included receipt of mammography and tested the revised scale with African American women. They found that unique issues existed for African American women around mammography scheduling and understanding of the mammography procedure.

McGarvey and colleagues (2003) used the HBM as a framework to study breast cancer screening behavior and attitudinal variables among low-income women from three different ethnic groups (Hispanic, Vietnamese, and Cambodian). Results from McGarvey et al.'s (2003) study showed that, when compared to the normative sample (Champion's [1993] study sample), Hispanic, Vietnamese, and Cambodian women ( $n = 78$ ) perceived cancer to be more serious than the normative group. Hispanic and Cambodian women believed that they were more susceptible to getting cancer than the normative group, while Vietnamese women believed they were less susceptible to getting cancer than the normative group. Interestingly, Hispanic and Vietnamese women were found to share more similarities than Vietnamese and Cambodian women in regards to breast cancer screening behavior (e.g., receipt of mammography). For example, Hispanic and Vietnamese both reported that cost and lack of health insurance were reasons for not obtaining a mammogram, while

Cambodian women reported transportation, the language barrier, and perception that cancer was not serious as major reasons for not obtaining a mammogram.

The use of the HBM to explore perception of risk and screening and vaccination behavior in regards to hepatitis B is limited. Most recently, Ma, Fang and colleagues (2007) used the HBM as a theoretical framework to assess risk perceptions and barriers to hepatitis B screening and vaccination among Vietnamese immigrants ( $n = 359$ ). They found that, in general, respondents did not perceive themselves to be at high risk for HBV infection despite the high infection rate in the Vietnamese population. Respondents also believed that hepatitis B infection would alter their lives, but were unsure whether infection could lead to liver cancer and death. In terms of perceived benefits, respondents believed that screening would help in detection, treatment, and transmission of the disease to others. Factors that posed as barriers to screening and vaccination included lack of knowledge about HBV infection, lack of information about where to get screened and vaccinated, fear of having a positive test result, language, and belief that screening is unnecessary if one is healthy. Furthermore, their study results showed that participants who had been screened were more likely to perceive themselves at higher risk for HBV infection, believed that HBV infection was more serious, and had fewer perceived barriers and more cues to action for HBV screening than participants who had not been screened for HBV. In regards to vaccination behavior, respondents who were not vaccinated were more likely to report that they did not know where to go to get vaccinated and that they did

not feel that they had to get vaccinated because they felt well compared to vaccinated respondents.

Hwang and colleagues (2008) conducted a survey with Vietnamese college students to address students' knowledge, attitudes, and screening behaviors with regards to hepatitis B infection. They found that, although more than half of respondents knew the routes of HBV transmission and most respondents were aware that HBV can lead to liver cancer, less than a third (29.9%) of respondents knew that Asian Americans are at higher risk for hepatitis B infection than were whites. Acculturation was also a factor in predicting receipt of a hepatitis B vaccination. Results showed that less acculturated Vietnamese students were less likely to have been vaccinated for hepatitis B.

In a study assessing predictive factors on childhood hepatitis B immunization among Korean American children using the HBM as a guiding framework, Kim and Telleen (2001) found that mothers' health beliefs were significantly related to childhood hepatitis B immunization status. For example, mothers of children who had completed the three-shot hepatitis B immunization series perceived more benefits of preventive health care services and perceived fewer barriers to health services than mothers of children who were not up-to-date on hepatitis B immunizations. Significant barriers to obtaining the hepatitis B vaccination reported by respondents included cost of immunization, language barriers (e.g., difficulty communicating in English at doctor's office), and difficulty remembering the immunization schedule. Perceived susceptibility and severity of hepatitis B in children were not significant

predictors of hepatitis B immunization (Kim & Telleen, 2001). They also looked at mothers' social support network in predicting preventive health behaviors (i.e., children fully immunized against hepatitis B) and found that mothers of children who received all three hepatitis B immunizations were more likely to have someone who gives advice and/or information about parenting and health care of children.

### *The Explanatory Models Approach*

The third approach used to guide the theoretical framework of this study is Arthur Kleinman's *Explanatory Models Approach* (Kleinman, Eisenberg, and Good, 1978; Kleinman, 1988). The explanatory models approach was first introduced by Kleinman in the early 1970s and is widely used in the fields of anthropology, psychology, and sociology and is often used in biomedicine and clinical training settings as an interview technique that tries to understand how the social world affects and is affected by illness (Kleinman et al., 1978; Kleinman & Benson, 2006b). The concepts of this approach are derived from anthropological and cross-cultural research and are used as a complimentary framework to the biomedical model in order to better understand and treat illness (Kleinman et al., 1978).

The premise behind the explanatory models approach is that the illness experience is shaped by culture; therefore, it is a culturally constructed concept (Kleinman et al., 1978), in which, our cultural orientation shapes how we understand our illnesses, influences our health related behaviors and values, and, in turn, affects how we treat and manage our illnesses. Culture matters because cultural factors are

crucial in understanding how patients comprehend diagnoses and cope with illness; it guides the treatment process; and it is essential to providing effective medical care to the patient (Kleinman, 1988; O'Mahoney & Donnelly, 2007). For example, in the Hmong language, there are a variety of terms that are used with the word "liver" (*siab*) to express emotions, mental health symptoms, attitudes, and certain behaviors (Bliatout, 1986 in Cha, 2003; Culhane-Pera & Xiong, 2003). Hmong terminology for liver problems associated with mental health symptoms are presented in Table 2.2. Furthermore, the illness experience is distinctive to each person and depends on the person's knowledge about the body and its pathologies (Kleinman, 1988).

Table 2.2  
*Hmong Terminology for Liver Problems*

Hmong Term	Literal Translation	Symptoms
<i>siab phem</i>	ugly liver	Destructive behavior, verbal abuse
<i>nyuab siab</i>	difficult liver	Excessive worry, crying, confusion, disorganized speech, loss of sleep, poor appetite, delusions
<i>tu siab</i>	broken liver	Suffering from grief or guilt, worry, loneliness
<i>siab luv</i>	short liver	Extreme temper, violent behavior
<i>kho siab</i>	mummuring liver	Displays nervous habits (e.g., pacing, humming, shaking), may be suicidal
<i>lwj siab</i>	rotten liver	Unhappy, short temper, delusions, loss of memory

*Note.* From D. Cha, 2003, *Hmong American Concepts of Health, Healing, and Conventional Medicine*. New York: Routledge, p. 45.

### *Biomedical Explanation vs. Patient Explanations*

Kleinman and his colleagues (1978) explain that *illness* is an explanation of a person's disorder from a patient perspective and is a personal, interpersonal, and cultural reaction to disease or discomfort; whereas, *disease* is a biomedical category

used by physicians to label a lived experience into a medical pathology. Patients view illness problems as constituting an entire disorder, whereas doctors disregard illness problems because they look upon the disease as the disorder (Kleinman et al., 1978). The illness experience is more than just a biological condition for the patient, it is a life altering experience that not only disrupts the patient's world, but perhaps all of those around him/her as well (Kleinman, 1988; Kleinman & Benson, 2006b). The biomedical model of treating the disease has not worked for the layperson (Kleinman et al., 1978; Kleinman, 1988; Kleinman & Benson, 2006b); thus, Kleinman's approach serves as a method to better understand the patients' perspective and health beliefs. According to Kleinman et al. (1978), each person has a set of personal views or an explanatory model that includes her/his beliefs about "1) etiology 2) onset of symptoms 3) pathophysiology 4) course of illness (including type of sick role – acute, chronic, impaired – and severity of disorder) and 5) treatment" (p.256). A goal of the explanatory models approach is to start a conversation between the provider and the patient and encourage a positive collaboration (for treatment) between the two (Kleinman & Benson, 2006a).

### *The Patient Model*

Eliciting the patient model provides health care providers a clearer understanding of the beliefs that patients hold about their illness, the personal and social meaning patients attach to their disorder, expectations about what will happen to them, how the provider will treat them, and how patients define their own treatment

process (Kleinman et al., 1978). Because patients are not always forthcoming about their condition or problems, Kleinman developed a series of questions to help elicit the patient's explanatory model (Table 2.3) (Kleinman, 1988). Furthermore, comparison of the patient model with the doctor's model enables the provider to identify discrepancies that may cause problems in her/her prescribed treatment and disease management (Kleinman, 1988). The patient model helps identify what needs to be explained in laymen terms to the patient about his/her diagnosis and treatment and how best to educate the patient and his/her family in order to help the patient (Kleinman, 1988).

Table 2.3

*Explanatory Models Approach Questions*

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Questions

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What do you call this problem?

What do you believe is the cause of this problem?

What course do you expect it to take?

How serious is it?

What do you think this problem does inside your body?

How does it affect your body and your mind?

What do you most fear about the treatment?

What do you most fear about this condition?

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*Note.* From A. Kleinman, 1988, *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books, p. 239.

In summary, knowledge of hepatitis B may vary among the Hmong and, as such, so will their hepatitis B screening and vaccination status. The decision to get screened and vaccinated may be influenced by multiple factors; therefore, an ecological approach is used in this study. In addition, the HBM is used as a theoretical framework in assessing perceived risk of hepatitis B infection and liver cancer and barriers to hepatitis B screening and vaccination among the Hmong. More

specifically, this research focused on the HBM constructs of perceived susceptibility and severity, perceived benefits, perceived barriers, and cues to action as they relate to hepatitis B screening and vaccination behavior. Lastly, the Explanatory Models Approach guided the qualitative questions to elicit Hmong people's beliefs and understanding about hepatitis B.

### Research Objectives and Hypotheses

Studies suggest that hepatitis B and liver cancer are serious public health problems in the Hmong population (Butler et al., 2005; Gjerdingen & Lor, 1997; Hurie et al., 1992; Miller et al., 2008; Mills et al., 2005). Hepatitis B prevalence rates are dramatically high among the Hmong, and screening and vaccination rates are extremely low (Butler et al., 2005; Gjerdingen & Lor, 1997; Hurie et al., 1992). The lack of knowledge among the Hmong in relation to disease transmission and prevention contributes to the burden of high hepatitis B infection rates. The objectives of this study were to explore 1) cultural beliefs and knowledge of hepatitis B and liver cancer, 2) perceptions of risk of hepatitis B infection, and 3) barriers to hepatitis B screening and vaccination among Hmong residing in Oregon. In addition, this study tested the following hypotheses:

- 1) Perceived susceptibility and severity of HBV infection will be positively associated with (a) HBV screening and (b) HBV vaccination.
- 2) Perceived benefits of obtaining HBV screening and vaccination will be positively associated with (a) HBV screening and (b) HBV vaccination.



- 3) Perceived barriers to obtaining HBV screening and vaccination will be negatively associated with (a) HBV screening and (b) HBV vaccination.

The long-term goal was to use the findings from this study to design and implement programs to reduce the burden of HBV infection and liver cancer in the Hmong population. In addition, the findings could help inform future research on these topics with the Hmong population.

## CHAPTER 3. METHODS

This mixed methods study examined Hmong knowledge and beliefs about hepatitis B and liver cancer, and barriers to hepatitis B screening and vaccination. The study piggybacked onto another research project conducted with Oregon's Hmong population on the topic of breast and cervical cancer. In other words, data collection for this research was added to the data collection plans of the Hmong Breast & Cervical Cancer Project (hereafter the BCC project). Accordingly, this chapter begins with a description of the BCC project including a description of that project's target population, data collection methods, and data management procedures. Next, the present study's interview questions and measures are presented, followed by a description of the data management procedures. Finally, data analyses are discussed.

### The Hmong Breast & Cervical Cancer Project

The BCC project is an exploratory study funded by the National Cancer Institute (NCI). The project, which started in March 2009, is a qualitative study that focuses on the potential influence of factors known to be important in Hmong culture (e.g., historical experience, gender roles), as well as health care system barriers that may be especially challenging for this population. Interviews were conducted first with key informants (i.e., community leaders, health care providers, and other knowledgeable persons). Building on those interviews, in-depth interviews were

conducted with Hmong women and men who resided in the Portland Metro (i.e., Multnomah, Clackamas, and Washington Counties) and Salem areas (Marion County). Field research activities were based out of the Asian Family Center, a well-known and highly regarded community-based center in Portland. The Asian Family Center also hosted team and community advisory committee meetings, and in essence served as a liaison with Hmong community members. The Oregon State University (OSU) Institutional Review Board (IRB) approved the study.

The long-term goals of the BCC study were to improve understanding of the factors that influence BCC screening behavior among Hmong women and to inform the development of culturally appropriate and relevant BCC interventions and services for Hmong. The project's specific aims were to: 1) examine how historical discrimination, medical mistrust, and perceptions of and experiences with the health care system influence Hmong women's attitudes and behavior related to breast and cervical cancer screening; 2) identify health care system factors (e.g., accessibility, structural impediments) that are barriers to breast and cervical cancer screening for Hmong women, the interface between those factors and health literacy, and the ways those factors contribute to mistrust and other negative perceptions of medicine and health care; and 3) explore the influence of primary groups, especially men (e.g., husbands, sons, fathers, elders), on Hmong women's attitudes, decision-making and behavior related to breast and cervical cancer screening, including the ways primary groups reinforce or help overcome barriers to cancer screening.

### *Target Population*

The target population for the BCC project was Hmong women and men (aged 18 years or older) living in Oregon. At the time of the study's design, input from Hmong community and clan leaders indicated that there were approximately 3600 Hmong living in Oregon. Most Hmong live in the Portland Metro area, with an estimated 300 residing in Salem, Oregon with familial ties to Hmong in the Portland area (B. Bliatout, personal communication, August 10, 2005). Oregon is one of several states with Hmong populations between 1,000 and 5,000 (Pfeifer, 2001). Portland-Salem has one of the 10 largest Hmong populations in the Western states (Pfeifer, 2001).

### *Community Advisory Committee*

A Community Advisory Committee, or the CAC, was established to help guide the BCC project. The CAC consists of nine individuals from the Hmong community who hold leadership positions, are knowledgeable about the community, and/or are interested in breast and cervical cancer. The CAC has worked with the BCC research team since the start of the project and has helped to ensure that the project was culturally sensitive and responsive to the Hmong community.

The role of the CAC was to help identify community assets (e.g., resources, organizations) to support the project, assist in developing a complete list of Hmong clans in Oregon, assist with identifying recruitment sites and methods, and provide input into the development of culturally appropriate and relevant measures and data

collection procedures. The CAC also helped introduce the project to the community and participated in problem-solving with the research team. Once analysis is completed, the CAC will assist in translating study findings into recommendations for programs and services and will provide input on how to share the results back to the community.

### *Key Informant Interviews*

In the first phase of data collection (July and August 2009), key informant interviews were conducted with all of the CAC members. Additional potential key informants were recruited through one of the investigators (author) who is actively involved in the Hmong community. Potential key informant participants had to be 18 years of age or over and live in Oregon; there were no other eligibility requirements. Seventeen key informant interviews (seven women and 10 men) were conducted, all key informants were Hmong, and represented eight of the 17 clans identified in Oregon. Key informants were offered \$25 in cash for their participation, up to \$10 for transportation, and up to \$10 for childcare costs.

A semi-structured interview guide was developed and included questions on historical discrimination, medical mistrust, perceptions of and experiences with the health care system, health care system barriers, health literacy needs with respect to BCC screening, and how members of primary groups influence women's attitudes, decision-making, and behavior related to BCC screening. The focus of the key informant interview questions was on the beliefs, attitudes, and experiences of

Hmong, in general, rather than on key informants' personal beliefs and experiences. The investigators conducted the key informant interviews mostly in English. The face-to-face interviews were conducted either in the key informants' home or office, in private rooms at the Asian Family Center, or other community locations (e.g., Hmong church). A written informed consent was obtained from each key informant before the interview began. The interviews were digitally recorded and lasted between one and one half hours and three hours. After the completion of each interview, the investigators wrote a brief summary of how the interview went and discussed with the research team issues or concerns that occurred, and then made revisions to the key informant interview guide. Key informant interviews were transcribed verbatim by project staff at OSU or an outside professional transcription firm in California.

### *In-depth Interviews*

In-depth interviews were conducted between December 2009 and May 2010. A total of 84 in-depth interviews were completed with Hmong women and men; however, data from one participant was not useable. Two individuals were screened, but did not qualify because they did not reside in Oregon. The final sample consisted of 44 women and 39 men ( $n = 83$ ). Our objective was to interview women and men, both younger (18-39 years) and older (40+ years), with 20 participants per gender/age group. To be eligible for the study, participants had to 1) self-identify as Hmong, 2) be aged 18 years or older, and 3) live in Oregon.

Bilingual and bicultural research staff recruited participants and conducted the interviews. Recruitment methods included both written and oral communication. For example, printed recruitment materials describing the project and contact information (e.g., postcards, posters) were placed at various community locations frequented by the Hmong community. Research staff made announcements and passed out brochures at community gatherings. Research staff recruited potential participants at community meetings and functions (e.g., church) and informal gatherings (e.g., clan new year celebrations), through programs offered at the Asian Family Center, and by referrals.

The interviews took place either in the participants' home or in a private room at the Asian Family Center, public library, or other community locations. Based on prior knowledge of the Hmong community in Oregon, we knew that not all participants would be able to read English and not all would be able to read Hmong, and, because using a witness to obtain informed consent would raise issues of violating confidentiality, we obtained a waiver of documentation of informed consent from OSU's IRB. Once questions or concerns were answered and potential participants agreed to take part in the study, the interviewer signed the consent form. The interviews were digitally recorded and took approximately 45 minutes to two hours to complete. Participants were offered \$25 cash to compensate them for their time and up to \$10 for transportation and up to \$10 for childcare costs.

Semi-structured in-depth interview guides (different versions for women and men) were developed based on findings from the key informant interviews and in

consultation with the CAC and other project consultants. The interview guide was in English only. The rationale for not having the interview guide translated into Hmong was based on our knowledge of the Hmong community in Oregon in which we expected that 1) all in-depth interview participants would understand spoken Hmong, but many would not be able to read Hmong; 2) some participants, particularly the younger generation, would prefer to speak in English; 3) some older participants may not understand or speak English; and 4) at the time of the design of the study, we felt that it would be challenging to recruit interviewers who could read Hmong. In addition, based on our discussions with the CAC, bilingual and bicultural interviewers would be able to verbally translate the interview guide as they asked the questions during the interview. The semi-structured guide consisted of primarily open-ended questions that asked participants about their own beliefs, attitudes, and experiences, covering similar topics as did the key informant interview guide, including historical discrimination, medical mistrust, health care system barriers, health literacy related to BCC screening, and how primary groups influence women's attitudes, decision-making, and behavior around BCC screening. In addition, the interview guide included demographic variables such as gender, age, education, length of residency in Oregon, and language proficiency.

### *Data Management*

Several steps were taken to ensure data quality and maintain participants' confidentiality. First, identification numbers were given to key informant and in-depth



interview participants to protect their identity. Interviewers were also trained on issues such as confidentiality and interviewing.

The data files were assigned only identification numbers and no other identifying information. All materials related to the BCC project (e.g., interview guides, transcriptions) were stored in a locked file cabinet at the OSU research office. Similar security protocol was implemented at the Asian Family Center until the materials could be transferred in-person to the research office at OSU.

In-depth interviews were conducted in Hmong, English, or a combination of both. Interviewers also prepared a brief written summary after completing each interview (Krueger, 1988). Interviews that were conducted in English were transcribed verbatim by project staff at OSU or through a professional transcription company in California. The interviews that were conducted in Hmong were translated into English and transcribed by a bilingual translator/transcriber at a professional transcription company in Minnesota. Steps were taken to ensure that the interviews were accurately transcribed and that procedures were followed (e.g., removal of identifying information). First, for the English transcripts, a project staff member listened to large portions of the transcribers' first transcribed interviews, made revisions on the transcripts, and provided feedback to the transcribers. The transcribers then made the necessary revisions. Then for subsequent interviews, the project staff checked the transcription quality for every 1 of 5-7 interviews, made revisions as necessary, and provided feedback to the transcribers. For the Hmong to English transcripts, one investigator who understood and spoke Hmong (the author)

reviewed the first three transcripts and gave feedback to the bilingual transcriber. Once the transcriber made the necessary revisions, the investigator then re-checked the new transcription to make sure the translations accurately reflected the audio recording. The investigator checked every 1 of 5 subsequent transcripts following the same procedures described above.

### Design and Rationale for Hepatitis B and Liver Cancer Study

As noted earlier, the study used a mixed methods approach in collecting and analyzing the data. More specifically, open-ended interview questions on study topics were added to the BCC key informant interview guide and open- and closed-ended questions were added to the BCC in-depth interview guide. By integrating both qualitative and quantitative data, this research provided a fuller picture and deeper understanding of the health issue at hand (Creswell & Plano Clark, 2006). Furthermore, by using both methods, a greater understanding of the Hmong culture and how their cultural beliefs influence their screening and vaccination behavior related to hepatitis B was gained. More specifically, open-ended questions explored topics such as meaning of disease (i.e., HBV and liver cancer) and personal experiences related to hepatitis B and liver cancer. Participants shared their perspectives and experiences in their own words, providing explanations and context for their beliefs, attitudes, and behavior. Close-ended questions provided additional

descriptive data on the knowledge of hepatitis B and liver cancer, disease transmission, and perception of risk of HBV infection.

In addition, the quantitative data were used to provide descriptive information, examine the associations between variables, and test the study hypotheses. Qualitative data enriched the research findings by exploring the experiences of Hmong in relation to hepatitis B and liver cancer and the factors that influence their screening and vaccination behavior, such as cultural beliefs and practices or barriers. In essence, a mixed methods approach provided a more holistic picture of Hmong's understanding of hepatitis B and liver cancer than could have either qualitative or quantitative approaches alone (Creswell & Plano Clark, 2006; Johnson & Onwuegbuzie, 2004).

### Key Informant Interview Measurement

Key informants were asked questions about the Hmong community's understanding, beliefs, and health practices related to hepatitis B and liver cancer. Hepatitis B and liver cancer questions were placed near the end of the key informant interview guide in their own section, following the questions about BCC and before questions on project logistics and sociodemographics. Key informants were asked the following questions, which are also found in Appendix A.

### *Hepatitis B Knowledge*

To better understand what Hmong people's knowledge of hepatitis B was, key informants were asked questions such as, "How would you say or describe hepatitis B in Hmong?," "How much do Hmong people know about hepatitis B?," and "What are Hmong beliefs about how hepatitis B infection is spread?" These questions were followed by probes about differences for men and women and older and younger Hmong.

### *Hepatitis B Screening Measurements*

Items on screening behavior included: 1) What are Hmong beliefs about how hepatitis B is prevented? 2) What is Hmong people's understanding about the hepatitis B testing process? 3) What is their understanding about who should be tested? 4) What is their understanding about why testing is necessary? and 5) What are ways that family and clan influence a person's decision to get tested for hepatitis B?

### *Hepatitis B Vaccination Measurements*

Vaccination behavior items included: 1) What is Hmong people's understanding about the hepatitis B vaccination? 2) What is their understanding about who should be vaccinated? 3) What is their understanding about why vaccination is necessary? 4) What are Hmong beliefs of how hepatitis B is treated by Western medicine? 5) What are traditional ways of treating hepatitis B infection? 6) and What

are ways that family and clan influence a person's decision to get vaccinated for hepatitis B?

### *Liver Cancer Knowledge Measurements*

Key informants were asked questions pertaining to liver cancer, including 1) How would you say or describe liver cancer in Hmong? 2) What do Hmong people think causes liver cancer? 3) What are Hmong beliefs about how liver cancer is treated by Western medicine? 4) What are traditional ways of treating liver cancer? and 5) What are ways that family and clan influence a person's decision-making related to liver cancer treatment? Probes about differences for men and women and older and younger Hmong followed the questions.

Information gained from the key informant interviews informed the development and refinement of the hepatitis B and liver cancer questions in the in-depth interview guide, which are described below.

### **In-depth Interview Measurement**

Open- and close-ended questions asked participants about their own knowledge of, beliefs, and behavior in regards to hepatitis B and liver cancer. These questions were included in the in-depth interview guide and can also be found in Appendix B. Open-ended questions are first presented below, followed by a discussion of close-ended questions.

### *The Meaning of Hepatitis B and Liver Cancer Measurements*

Questions for the in-depth interviews were adapted from several sources (Burke et al., 2004; Choe et al., 2006; Kleinman, 1988). Measurements to explore the meaning of hepatitis B and liver cancer included Kleinman's (1988) Explanatory Models Approach items, such as: 1) What do you call this problem in Hmong? 2) What do you believe is the cause of hepatitis B? 3) How do you think your condition will progress? 4) How serious is it? 5) What do you think hepatitis B does inside your body? 6) How does it affect your body and your mind? 7) What do you most fear about hepatitis B? 8) What do you most fear about hepatitis B? and 9) What do you most fear about the treatment?

Items about liver cancer included: 1) Has a doctor or health care provider ever told you that you have liver cancer? 2) When you hear the words liver cancer what does it mean to you? 3) What is your understanding of the causes and symptoms of liver cancer? and 4) Thinking about the people you know, such as family and friends, do you know Hmong people in the U.S. who have had liver cancer? Probes for the last question included: "What are/were those experiences like for them?" and "Do they know what caused their condition?"

### *Hepatitis B Sequelae Knowledge Measurements*

Items about knowledge of hepatitis B have been adapted or taken verbatim from instruments used to survey Cambodian (Taylor et al., 2002), Vietnamese (Ma, Shive et al., 2007), and Hmong (Butler et al., 2005) populations. Of the existing

instruments used to assess knowledge and beliefs about hepatitis B among Southeast Asian populations, the only instrument known to have been tested for validity and reliability was Ma, Shive and colleagues' (2007) hepatitis B survey. The instrument was tested for face validity based on comments from pilot test participants (Ma, Shive et al., 2007). The instrument was tested for internal reliability with a Spearman rho (.65) on demographic variables (i.e., educational level and household income) and Cronbach's alpha (.94) on screening behavior items (i.e., ever getting screened and when did you get screened, and ever getting screened and screening results), indicating high reliability for measurement of screening behavior (Ma, Shive et al., 2007).

For this study, hepatitis B sequelae knowledge was measured with the following four items: 1) Do you think hepatitis B causes liver cancer? 2) Do you think people with hepatitis B can be infected for life? 3) Do you think someone can die from hepatitis B? and 4) Do you think a person infected with hepatitis B can be cured? (Butler et al., 2005; Ma, Shive et al., 2007; Taylor et al., 2002). Response categories were yes, no, and don't know. Scores were calculated for sequelae knowledge with a total score that ranged from 0 to 4. For each correct answer, a 1 was assigned, and a 0 for each answer marked wrong or don't know. A summary score was computed for each respondent by adding the points for each item with high knowledge scores reflecting more accurate knowledge of sequelae.

### *Hepatitis B Transmission Knowledge Measurements*

Items measuring knowledge of hepatitis B transmission were taken from Taylor et al.'s (2002) and Ma, Shive et al.'s, (2007) instruments. Taylor and colleagues' (2002) instrument included 11 items that assessed knowledge of virus transmission; however, only 10 items were used in this study due to the nature of the omitted question. The omitted question asked, "Which do you think is more easily spread from person to person: hepatitis B or the acquired immunodeficiency syndrome (AIDS) virus?" This item was not included because it is not relevant to the study and Taylor and colleagues' study is the only one to ask this particular question. Reliability and validity information were not available for Taylor and colleagues' instrument.

Hepatitis B transmission items for in-depth interview guide included: "If someone is infected with the hepatitis B virus, but they look and feel healthy, do you think that person can spread the hepatitis B virus?" and "Do you think the hepatitis B virus can be spread from person to person: a) by eating food prepared by the infected person?, b) by sharing a toothbrush with an infected person?, c) by eating food that has been pre-chewed by an infected person?, d) by being coughed on by an infected person?, e) by sharing razors with an infected person?, f) by having sexual intercourse with an infected person?, g) when intravenous drug users share needles with each other?, and h) by holding hands with an infected person?" Items from Ma, Shive and colleagues' (2007) instrument that were used included knowledge about whether or not the virus can be spread: a) from mother to child during birth, and b) by sharing food plates with someone who is infected. Response categories were yes, no, and



don't know. Similar to the measures for sequelae knowledge, a summary score was computed for the questions addressing hepatitis B transmission. A 1 was assigned to each correct answer and 0 for each answer marked wrong or don't know. The score consisted of the total number of correct answers; therefore, the maximum score for transmission knowledge was 11.

### *Hepatitis B Screening and Vaccination Measurements*

Hepatitis B screening and vaccination status were assessed by the following two items taken from Hwang and colleagues' (2008) instrument conducted with Vietnamese college students on predictors of HBV vaccination: "Have you ever been tested for hepatitis B?" and "Have you ever been vaccinated against hepatitis B?"

Response categories were yes, no, and don't know. Participants who reported having been screened or vaccinated were asked to describe their experiences with the following questions: 1) In getting tested/vaccinated for hepatitis B, what things do you feel made it difficult for you to get tested/vaccinated? 2) What things made it easy? Furthermore, to assess hepatitis B status, participants were asked, "Has a doctor or other health care provider ever told you that you have hepatitis B?" Response categories were yes, no, and don't know. For data analysis, only *yes* and *no* responses were examined.

*Health Belief Model Measurements*

Participants' perceived susceptibility, severity, benefits and barriers, and cues to action in relation to hepatitis B infection were assessed with measures adapted from Ma, Fang et al.'s (2007) instrument. At the time this study was designed, Ma, Fang et al.'s original survey instrument was not accessible; therefore, the questions that address the HBM components for the current study were adapted from the information available in Ma, Fang et al.'s published articles.

For this study, three items from Ma, Fang et al.'s (2007) instrument were used to measure one's perceived susceptibility of hepatitis B. Participants were asked to respond to the following statements: 1) I feel that I am at high risk for hepatitis B infection, 2) I worry about getting hepatitis B, and 3) I worry about getting liver cancer.

Two items were used to measure one's perceived severity of hepatitis B. These items included: 1) My life would change if I had hepatitis B, and 2) People infected with hepatitis B will die from liver cancer.

Five items were used to measure perceived benefits to screening and vaccination. Participants were asked: 1) Getting tested is an effective way to detect hepatitis B infection, 2) Getting tested prevents transmission of hepatitis B to others, 3) Getting vaccinated for hepatitis B reduces worry about liver disease, 4) Vaccination is the best way to prevent liver cancer, and 5) Early detection will make it easier to treat hepatitis B infection.

Four items were used to measure perceived barriers to hepatitis B screening and vaccination and included: 1) Language is a barrier for me to get screened and vaccinated for hepatitis B, 2) I do not know where to get screened and vaccinated for hepatitis B, 3) I am scared to find out if I test positive for hepatitis B, and 4) Screening is not necessary if I feel well.

Using a five-point Likert scale, from *strongly disagree* to *strongly agree*, participants rated how much they agreed with each of the statements described above. A response card for HBM questions was developed in English and translated into Hmong, with English response categories on the front and Hmong on the back of the card. A composite score for each of the HBM subscale was created by taking an average of items in that subscale, with higher scores indicating greater perceived susceptibility, severity, barriers and benefits (Ma, Fang et al., 2007). Responses that indicated a *don't know* or *not sure* opinion were not included in the composite score.

To test the internal consistency of the HBM components, Cronbach's alphas were computed for each subscale (Portney & Watkins, 1993). Internal consistency of HBM subscales were  $\alpha = .81$  for perceived susceptibility,  $\alpha = .69$  for perceived benefits, and  $\alpha = .61$  for perceived barriers. The reliability test for the perceived severity scale produced a low internal consistency,  $\alpha = .32$ ; thus, the individual questions rather than the scale score was used in the bivariate and multivariate regression analyses to examine the perceived severity and screening and vaccination. Furthermore, responses to perceived severity questions, *my life would change if I had hepatitis B* and *people infected with hepatitis B will die from liver cancer*, were

dichotomized (disagree and agree). Responses that included *strongly disagree*, *disagree*, and *neutral* were collapsed into the response category of *disagree*.

Responses that included *agree* and *strongly agree* were collapsed into the response category of *agree*. *Don't know/not sure* responses were categorized as missing.

Cues to action and screening and vaccination behavior included the following three items: 1) Has a doctor or other health care provider ever told you that you should be tested for hepatitis B? 2) Do you have a family member who has hepatitis B? and 3) Have you attended a hepatitis B education workshop in the past? Response categories were yes, no, and don't know. A summary score for cues to action was developed where a score of 1 was assigned to each *yes* response and a score of 0 was assigned to each *no* or *don't know* response, allowing a possible of 0-3 cues to action (Ma, Fang et al., 2007).

### *Linguistic Acculturation Measurements*

Linguistic acculturation was measured with items taken from the 13-item scale developed by Anderson and colleagues (1993) specifically for Southeast Asians.

Anderson and colleagues' scale was developed from the responses of Cambodian, Lao, and Vietnamese. Anderson and colleagues (1993) developed two acculturation subscales: 1) language proficiency (both English and native language) and 2) language, social, and food preferences. The first subscale included items on language proficiency (i.e., understanding, speaking, reading, and writing) in English and in the language of origin (i.e., Cambodian, Lao, and Vietnamese). The second subscale

included language most used with spouse, children, parents, friends, neighbors, at work and at family gatherings; and type of close friends, coworkers, and neighbors seen nearly every day (more from their culture of origin or “American”) and one item on food preference (Anderson et al., 1993, p.135). A Likert-type scale was used to measure all the items.

In this study, only the language proficiency subscales (both English and native language) were used. The items were: “In your opinion, how well do you understand, speak, read, and write English?” and “In your opinion, how well do you understand, speak, read, and write in Hmong?” Response categories were based on a five-point Likert scale with 1 equal to *not at all* and 5 equal to *very well*.

Missing data were most problematic for the language proficiency variables, specifically “understand English,” but also included missing cases for “speak English,” “understand Hmong,” and “speak Hmong.” Missing data for the English language questions (i.e., understand and speak English) were handled by replacing the missing value with the mean value for that question. The same method was used for replacing the missing values in the Hmong language questions. Using the mean in place of a missing value was not used for other missing values in other scales because the number of missing values was not as great as it was for the English and Hmong proficiency scales. Once missing data was replaced, a composite score was computed for each language proficiency scale.

To test the internal consistency of the linguistic acculturation scales (English and Hmong proficiency), Cronbach’s alphas were computed for each (Portney &

Watkins, 1993). The reliability test for English and Hmong proficiency scales produced an acceptable Cronbach's alpha of  $\alpha = .96$  and  $\alpha = .78$ , respectively.

### *Sociodemographic Items*

This study also analyzed sociodemographic data collected as part of the BCC project. Standard sociodemographic questions assessed participants' social and health status such as gender, age, years of education, years lived in Oregon, and health insurance status.

## Data Analysis

Hepatitis B and liver cancer results from key informant and in-depth interviews were analyzed separately from the BCC project. Qualitative data analysis addressed the meaning of hepatitis B and liver cancer and barriers to hepatitis B screening and vaccination. Quantitative data analysis was used to address knowledge, beliefs, and perceptions of risk of HBV infection. Analyses of qualitative and quantitative data are described below.

### *Qualitative Data Analysis*

Content analysis techniques were used to analyze both the key informant and in-depth interview data. All transcripts were entered, coded, and analyzed in QSR International's NVivo 8 (hereafter NVivo), a qualitative data management and

analysis program (QSR International, Cambridge, MA). First, for key informant interviews, codes were generated and refined with input from a research assistant. Then, two people coded the transcripts. Themes were identified and quotes that provided specific insight were then selected by the author.

For the in-depth interviews, codes were generated through a two-step process. The first step included having the author and a research assistant independently read three assigned transcripts. Then a list of words describing potential themes or ideas was constructed. The preliminary list of words were discussed, refined, and organized to generate a codebook. Second, the codebook was used to code all of the transcripts. Two coders coded each transcript. Potential new themes or ideas that emerged in subsequent transcripts were discussed by the two coders and if the theme or idea did not fit under any other codes, then a new code was established in NVivo. Using NVivo, matrices were generated for topics of interest, such as hepatitis B screening experience or meaning of liver cancer, and were categorized by age ( $< 40$ , and  $\geq 40$ ) and gender for comparison. Lastly, illustrative quotes were identified, and the findings were summarized.

### *Quantitative Data Analysis*

Once data collection was completed, the in-depth interview guides were reviewed to ensure that all quantitative questions were answered and that each question had no more than one answer unless stated otherwise. Data screening and verification were performed. The interview guides were compared to the transcripts

for discrepancies. Missing data were checked against the audio files and, if necessary, corrections were made. In cases where there were inconsistencies between the transcript and the interview guide, additions or corrections were made according to the audio. Using the interview guide, the data were then entered into PASW (formerly SPSS) version 18.0 (SPSS, Inc., 2008; Chicago, IL) one time, and then entered a second time to make sure there were no data entry errors.

Data analyses included univariate (descriptive), bivariate, and multivariate regression analyses. Variables with non-normal distributions were recoded or categorized. Age was collapsed from a continuous variable into a categorical variable (aged 18-39 and 40 + years). Education was also dichotomized (never attended-high school graduate/GED and some college and higher). In addition, the variables for the number of children in household were dichotomized (do not have children and have children).

First, descriptive statistics were used to summarize data collected for sociodemographic variables. Means were calculated for age, and frequencies and percentages were calculated for gender, marital status, and place of birth. Furthermore, frequencies were ran to examine the distribution of transmission and sequelae knowledge of hepatitis B, screening and vaccination behavior (e.g., have been screened or vaccinated), English and Hmong proficiency items, and HBM items (e.g., perceived susceptibility, severity, benefits, barriers, and cues to action).

Next, logistic regression analyses were conducted to determine the relationship between sociodemographic variables and screening behavior (screened/not screened).



Separate logistic regression analyses were performed for vaccination. Logistic regression analyses were also conducted to examine the relationship between each HBM component and screening and vaccination behaviors. In addition, bivariate analyses were conducted to examine the association between linguistic acculturation and screening behavior, vaccination behavior, and each HBM component.

Description of the analyses for the hypotheses follows.

*Hypothesis 1: Perceived susceptibility and severity of HBV infection will be positively associated with (a) HBV screening and (b) HBV vaccination.*

Multiple logistic regression analysis was used to examine the relationship of perceived susceptibility and perceived severity to screening behavior. Those sociodemographic and acculturation variables found to have significant relationships with the dependent variable (screened for hepatitis B) at  $p < .10$  in the bivariate analyses were included as covariates in the model. Unfortunately, some of the covariates that were found to have significant associations with screening behavior in the bivariate analyses (i.e., have health insurance and have been recommended by doctor to get screened) produced very wide confidence intervals; thus, based on recommendations by De Irala, Navajas, and Serrano del Castillo (1997), those variables were not included in the final model. Separate multivariate analyses were conducted for vaccination behavior. Similarly, covariates found to be significantly associated with vaccination at  $p < .10$  were included in the multivariate analysis.

*Hypothesis 2: Perceived benefits of obtaining HBV screening and vaccination will be positively associated with (a) HBV screening and (b) HBV vaccination.*

To test this hypothesis, multiple logistic regression analysis was conducted to

examine the relationship of perceived benefits to screening behavior. Similar to analyses for hypothesis 1, those sociodemographic and acculturation variables found to have significant relationships with the dependent variable at  $p < .10$  in the bivariate analyses were included as covariates in the model. Separate multiple logistic regression analysis was conducted to examine the relationship between perceived benefits and vaccination behavior. Variables found to have significant relationships with vaccination at  $p < .10$  in the bivariate analyses were included in the multivariate analysis.

*Hypothesis 3: Perceived barriers to obtaining HBV screening and vaccination will be negatively associated with (a) HBV screening and (b) HBV vaccination.*

Similar analyses of the first two hypotheses were conducted to test the final hypothesis. Variables found to have significant relationships with screening at  $p < .10$  in the bivariate analyses were included as covariates in the multiple logistic regression analysis. Again, separate multiple logistic regression analysis was conducted to examine the relationship between perceived barriers and vaccination. Variables found to have significant relationships with vaccination at  $p < .10$  in the bivariate analyses were included as covariates in the multivariate model.

#### *Additional Analyses*

Additional bivariate and multivariate analyses to determine the relationship between sociodemographic variables and linguistic acculturation variables were conducted using independent samples t-test and chi-square. Mean differences in transmission and sequelae knowledge by sociodemographic variables (e.g., age,

education) were assessed. Furthermore, the differences in transmission knowledge between those participants who had been screened versus those who had not were examined using independent samples t-tests. A separate analysis was performed for sequelae knowledge and screening. Similarly, the differences in transmission knowledge and sequelae knowledge between those participants who had been vaccinated versus those who had not were also examined using independent samples t-tests.

### *Power Analysis*

In this section, estimates of statistical power for sample bivariate and multiple regression analyses are presented. Estimates of power analyses were generated from information presented by Cohen (1992). For these estimates, .80 power and two-tailed testing at the .05 level are assumed. A sample size of 80 was determined to be sufficient for the bivariate and regression analyses with the quantitative data. For bivariate analyses, a sample size of 28 was sufficient to detect an  $r$  of .50 (corresponding to a large effect size). For example, a sample size of 28 in each group was sufficient when using t-test analysis to compare mean differences such as differences in perceived susceptibility for women and men. Using chi-square tests, a sample size of 54 was needed to detect a large degree of association ( $w = .50$ , 6 degrees of freedom) between, for example, gender and linguistic acculturation. In multiple logistic regression analyses with eight independent variables, a sample size of 50 was sufficient to detect an  $R^2$  of .35 (corresponding to a large effect size). To

detect a medium effect ( $R^2 = .15$ ) in multiple logistic regression analyses, a sample size of 76 was sufficient with three independent variables at power of .80.

As noted earlier, the sample size for this study was small ( $n = 83$ ) and is limited by the larger BCC project. As a result, the sample size will generally not be sufficient to detect small effects at power = .80 and  $\alpha = .05$  and may not have been sufficient to detect medium effects in some analyses. Despite this limitation, the analyses helped identify factors that may be associated with perceptions of risks and screening and vaccination behaviors related to hepatitis B, especially in combination with the qualitative data. Thus, this study may help fill a significant gap in knowledge about barriers to hepatitis B screening and vaccination among Hmong and provides direction for future quantitative research with larger samples.

## CHAPTER 4. RESULTS

This chapter reports the findings from the key informant and in-depth interviews conducted with Hmong women and men living in Oregon. To provide context, the quantitative results from the in-depth interviews, which explored knowledge and perceptions of risk of hepatitis B infection, are presented first. The quantitative results section is then followed by the qualitative findings from the key informant and in-depth interviews.

### Quantitative Data: In-Depth Interviews

This section begins with a description of the sociodemographic and hepatitis B characteristics of in-depth interview participants, followed by a description of participants' knowledge of hepatitis B transmission and sequelae. Next, results related to the relationship between the Health Belief Model (HBM) components and hepatitis B screening and vaccination behavior are presented.

#### *Participant Characteristics*

In-depth interview participant characteristics are shown in Table 4.1. Over half of participants were female. The average age was 38.8 years. About half had the equivalent of a high school education or lower, and the majority was married. More than half of the in-depth interview participants were born outside of the U.S. Over

four-fifths had health insurance, and more than half reported having a primary health care provider. The majority could understand, speak, read, or write English pretty well to very well. Although the majority understood and spoke Hmong fluently, more than half could not read or write in their native language very well.

Table 4.1  
*Participant Characteristics*

Characteristic	Total <i>n</i> (%) ( <i>n</i> = 83)
Gender	
Male	39 (47.0)
Female	44 (53.0)
Age in years, mean	38.8
18-39	45 (54.2)
40 and over	38 (45.8)
Education	
Never attended – HS Graduate/GED	41 (49.4)
Some college or more	42 (50.6)
Married	68 (81.9)
Place of birth	
Foreign-born	51 (61.4)
U.S.-born	32 (38.6)
Number of children < 18 years	
No children	26 (36.6)
Have children	45 (63.4)
Number of children ≥ 18 years	
No children	39 (54.9)
Have children	32 (45.1)
Have health insurance	69 (83.1)
Have a primary health care provider	51 (61.4)
Does seek preventive care	44 (53.0)
English proficiency	
Understand pretty well – very well ( <i>n</i> = 72)	58 (80.6)
Speak pretty well – very well ( <i>n</i> = 81)	63 (77.7)
Read pretty well – very well	60 (72.2)
Write pretty well – very well	58 (69.9)
Hmong proficiency	
Understand pretty well – very well ( <i>n</i> = 71)	69 (97.2)
Speak pretty well – very well ( <i>n</i> = 82)	64 (78.0)
Read pretty well – very well	41 (49.4)
Write pretty well – very well	33 (39.8)

### *Hepatitis B Experience and Status*

Table 4.2 presents hepatitis B characteristics of in-depth interview participants. Almost all had heard of the hepatitis B virus. Slightly more than half had been screened for hepatitis B, and half of the participants reported having been vaccinated. Almost two-thirds of in-depth interview participants had never received a doctor's recommendation to get screened, and less than 10% reported that they had attended a hepatitis B workshop in the past. Furthermore, less than 10% reported that they have hepatitis B.

Table 4.2  
*Hepatitis B Characteristics*

Characteristic	<i>n (%)</i> ( <i>n</i> = 83)
Ever heard of hepatitis B	
No	3 (3.6)
Yes	80 (96.4)
Screened for hepatitis B	
No	27 (32.5)
Yes	44 (53.0)
Don't know	12 (14.5)
Vaccinated for hepatitis B	
No	25 (30.1)
Yes	42 (50.6)
Don't know	16 (19.3)
Doctor recommended screening	
No	53 (63.4)
Yes	30 (36.6)
Family member who have hepatitis B	
No	44 (53.0)
Yes	31 (37.3)
Don't know	8 (9.6)
Ever attended hepatitis B education workshop	
No	75 (90.4)
Yes	8 (9.6)
Have hepatitis B	
No	76 (91.6)
Yes	7 (8.4)



*Sociodemographic and Health Care Characteristics and Screening Behavior*

Table 4.3 shows the odds ratios and 95% confidence intervals from logistic regression analyses used to determine the unadjusted association between sociodemographic and health care characteristics and screening behavior. To highlight a few of the findings, when compared to participants with lower levels of education, those with some college education or more were more likely (marginally significantly at  $p < .10$ ) to have been screened for hepatitis B. In addition, having health insurance was significantly associated ( $p < .05$ ) with screening. In fact, in-depth interview participants with health insurance were five times more likely to have been screened than those who did not have health insurance. Having sought preventive care was associated (marginally significant at  $p < .10$ ) with screening. Provider recommendation was also significantly associated with screening ( $p < .001$ ), in that those participants who had received a recommendation by a doctor to get screened were more likely to have been screened than those who did not receive a doctor's recommendation. Furthermore, English proficiency had a marginally significant association with screening, but Hmong proficiency was found to have no association.

Table 4.3  
*Bivariate Analysis of Sociodemographic and Health Care Characteristics and  
 Hepatitis B Screening Behavior*

Characteristic	$\beta$	SE	Screened for hepatitis B ( <i>n</i> = 71) OR (95% CI)
Gender			
Male			Referent
Female	-.47	.49	.63 (.24, 1.65)
Age in years			
18-39			Referent
40 and over	-.29	.49	.75 (.28, 1.96)
Education			
Never attended – HS graduate/GED			Referent
Some college or more	.84	.50	2.31 (.87, 6.15)*
Marital status			
Not married			Referent
Married	-.12	.62	.88 (.26, 2.98)
Place of birth			
Foreign-born			Referent
U.S.-born	.16	.50	1.18 (.44, 3.15)
Number of children <sup>a</sup>			
< 18 years			
No children			Referent
Have children	.45	.56	1.56 (.52, 4.70)
Number of children <sup>a</sup>			
≥ 18 years			
No children			Referent
Have children	-.06	.53	.95 (.34, 2.67)
Health insurance status			
No insurance			Referent
Have insurance	1.61	.67	5.00 (1.36, 18.39)**
Primary health care provider			
No provider			Referent
Have provider	.59	.50	1.80 (.67, 4.78)
Preventive care			
Does not seek preventive care			Referent
Does seek preventive care	.90	.50	2.46 (.92, 6.58)*
Doctor recommendation to get screened			
Have not been recommended			Referent
Have been recommended	2.45	.69	11.56 (3.02, 44.23)***
English proficiency composite score	.57	.33	1.77 (.93, 3.35)*
Hmong proficiency composite score	-.09	.37	.92 (.44, 1.90)

Note:  $\beta$  = beta; SE = standard error; OR = odds ratio; CI = confidence interval.

<sup>a</sup> *n* = 60 due to missing data.

\**p* < .10, \*\**p* < .05, \*\*\**p* < .001 according to the Wald test of significance.

*Sociodemographic and Health Care Characteristics and Vaccination Behavior*

Logistic regression analyses used to determine the unadjusted association between sociodemographic and health care characteristics and vaccination behavior are presented in Table 4.4. English proficiency was the only variable found to be significantly associated with having been vaccinated for hepatitis B.

Table 4.4  
*Bivariate Analysis of Sociodemographic and Health Care Characteristics and  
 Hepatitis B Vaccination Behavior*

Characteristic	$\beta$	SE	Vaccinated for hepatitis B (n = 67) OR (95% CI)
Gender			
Male			Referent
Female	-.24	.51	.79 (.29, 2.13)
Age in years			
18-39			Referent
40 and over	-.79	.52	.45 (.17, 1.25)
Education			
Never attended – HS graduate/GED			Referent
Some college or more	.79	.52	2.21 (.80, 6.06)
Marital status			
Not married			Referent
Married	.22	.65	1.25 (.35, 4.46)
Place of birth			
Foreign-born			Referent
U.S.-born	.66	.55	1.93 (.66, 5.60)
Number of children <sup>a</sup>			
< 18 years			
No children			Referent
Have children	.65	.56	1.92 (.64, 5.80)
Number of children <sup>a</sup>			
≥ 18 years			
No children			Referent
Have children	-.03	.54	.98 (.34, 2.82)
Health insurance status			
No insurance			Referent
Have insurance	.64	.64	1.90 (.54, 6.68)
Primary health care provider			
No provider			Referent
Have provider	.08	.52	1.08 (.39, 2.99)
Preventive care			
Does not seek preventive care			Referent
Does seek preventive care	.11	.51	1.12 (.41, 3.01)
Doctor recommendation to get screened			
Have not been recommended			Referent
Have been recommended	.27	.53	1.31 (.46, 3.72)
English proficiency composite score	.76	.35	2.14 (1.09, 4.20)*
Hmong proficiency composite score	.05	.38	1.05 (.50, 2.23)

Note:  $\beta$  = beta; SE = standard error; OR = odds ratio; CI = confidence interval.

<sup>a</sup> n = 58 due to missing data.

\*p < .05 according to the Wald test of significance.

*Participants' Knowledge of Hepatitis B Transmission and Sequelae*

A summary of the responses to the questions addressing transmission and sequelae are presented in Table 4.5. In general, more than half of in-depth interview participants were able to correctly identify modes of hepatitis B transmission. However, results show that there were still large gaps in knowledge about routes of transmission. For example, almost one-third of participants believed that if an infected person is asymptomatic, they would not transmit the virus to others. More than half incorrectly believed that the virus could be passed through coughing. In addition, nearly 45% of participants were not aware that the virus could be transmitted by sharing a razor with an infected person, and 40% did not know that hepatitis B could be transmitted through sexual intercourse. Furthermore, almost 20% did not know that HBV infection could occur from mother-to-child.

In terms of sequelae knowledge, many in-depth participants were unclear about what happens to a person as a consequence of hepatitis B infection. For example, nearly one-third of participants did not know HBV causes liver cancer. Furthermore, almost one-third of participants did not know that people with hepatitis B could be infected for life, and less than half recognized that it is incurable.

Table 4.5  
*Hepatitis B Transmission and Sequelae Knowledge*

Knowledge Variable	Correct Answer	% Correctly Answered (n = 83)
<i>Transmission</i>		
If someone is infected with the hepatitis B virus, but they look and feel healthy, do you think that person can spread the hepatitis B virus?	Yes	68.7
Do you think the hepatitis B virus can be spread from person to person:		
by eating food prepared by the infected person?	No	55.4
by sharing a toothbrush with an infected person?	Yes	59.0
by eating food that has been pre-chewed by an infected person?	Yes	62.7
by sharing food plates with someone who is infected?	No	51.8
by being coughed on by an infected person?	No	45.8
by sharing razors with an infected person? (n = 82)	Yes	55.4
by having sexual intercourse with an infected person?	Yes	60.2
when intravenous drug users share needles with each other?	Yes	85.5
by holding hands with an infected person?	No	89.2
from mother-to-child during birth?	Yes	80.7
<i>Sequelae</i>		
Do you think hepatitis B causes liver cancer?	Yes	67.5
Do you think someone can die from hepatitis B?	Yes	83.1
Do you think people with hepatitis B can be infected for life?	Yes	67.5
Do you think a person infected with hepatitis B can be cured?	No	45.8

*Bivariate Relationship Between Participant Characteristics and Hepatitis B Knowledge*

Bivariate analysis was conducted to examine the relationship of participant characteristics and transmission knowledge, and similar analysis was conducted for sequelae knowledge. For simplicity, Table 4.6 presents results for only those variables significantly related to transmission knowledge. Results show that transmission knowledge was significantly associated with age, place of birth, and preventive care. Younger participants (18-39 years) had a higher knowledge score than did older participants (40+ years). Those who were born in the U.S. also had higher knowledge of transmission routes than did those who were not. Furthermore, participants who sought preventive care had a higher knowledge of transmission score than did those who did not seek preventive care.

In terms of the association between sequelae knowledge and sociodemographic characteristics, only preventive care varied significantly (data not shown). On average, participants who sought preventive care had greater sequelae knowledge ( $M = 3.02$ ,  $SD = 1.02$ ) than did those who did not seek preventive care ( $M = 2.21$ ,  $SD = 1.20$ ) (data not shown). The difference was significant [ $t(81) = -3.36$ ,  $p < .01$ ].

Table 4.6  
*Bivariate Relationship of Participant Characteristics and Transmission Knowledge*

Characteristic	Transmission Score Mean (SD) ( <i>n</i> = 83)	<i>t</i>	<i>df</i>
Age			
18-39 years	7.60 (2.00)	2.24*	81
40 years and over	6.61 (2.05)		
Place of birth			
Foreign-born	6.53 (2.11)	-3.68**	81
U.S.-born	8.13 (1.58)		
Preventive care			
No, does not seek preventive care	6.31 (2.28)	-3.74**	81
Yes, does seek preventive care	7.89 (1.53)		

Note: SD = standard deviation; *df* = degrees of freedom; scale of 0-11.

\**p* < .05, \*\**p* < .001.

Additional bivariate analyses were conducted to examine the relationship between hepatitis B knowledge and screening behavior. Logistic regression analysis found no relationship between knowledge of hepatitis B and having been screened or vaccinated (data not shown). In addition, knowledge of transmission was not associated with screening or vaccination (Table 4.7). Similarly, sequelae knowledge was not associated with screening or vaccination.

Table 4.7  
*Bivariate Relationship Between Hepatitis B Knowledge and Screening and Vaccination Behavior*

Characteristic	Screened for hepatitis B ( <i>n</i> = 71)			Vaccinated for hepatitis B ( <i>n</i> = 67)		
	$\beta$	SE	OR (95% CI)	$\beta$	SE	OR (95% CI)
Transmission knowledge	.05	.11	1.06 (.85, 1.31)	.06	.12	1.06 (.84, 1.35)
Sequelae knowledge	.07	.21	1.07 (.71, 1.62)	-.20	.22	.82 (.53, 1.25)

Note.  $\beta$  = beta; SE = standard error; OR = odds ratio; CI = confidence interval.



*Cues to Action and Screening and Vaccination Behavior*

On average, participants received less than one cue to action (mean = .83), and only one participant received all three cues (data not shown). The bivariate relationship between hepatitis B cues to action and screening and vaccination behavior are shown in Table 4.8.

In terms of screening, results show that having received a recommendation by a doctor was significantly associated with screening for hepatitis. Having family members with hepatitis B and ever attending an educational workshop on hepatitis B were not associated with screening. In terms of vaccination behavior, cues to action items were not significantly associated with vaccination.

Table 4.8  
*Prevalence (%) of Cues to Action and Screening and Vaccination Behavior*

Cues to Action	Screened % (n = 44)	Not Screened % (n = 27)	$\chi^2$	Vaccinated % (n = 42)	Not Vaccinated % (n = 25)	$\chi^2$
Doctor recommended screening			15.94*			.25
No	40.9	88.9		61.9	68.0	
Yes	59.1	11.1		38.1	32.0	
Family members who have hep B			.00			.98
No	63.6	63.0		64.3	52.0	
Yes	36.4	37.0		35.7	48.0	
Ever attended hep B education workshop			.70 <sup>a</sup>			.46 <sup>a</sup>
No	86.4	92.6		90.5	84.0	
Yes	13.6	7.4		9.5	16.0	

Note: <sup>a</sup> Fisher's Exact Test.

\* $p < .001$ .

In addition, logistic regression analyses were conducted to examine the relationship between cues to action score and screening behavior (Table 4.9). Results showed that there was a significant association between cues to action and screening.

Table 4.9

*Relationship Between Cues to Action Score and Screening and Vaccination Behavior*

Characteristic	Screened for hepatitis B ( <i>n</i> = 71)			Vaccinated for hepatitis B ( <i>n</i> = 67)		
	$\beta$	SE	OR (95% CI)	$\beta$	SE	OR (95%CI)
Cues to Action Summary Score	1.13	.40	7.89* (1.41, 6.77)	-.24	.35	.79 (.40, 1.56)

Note.  $\beta$  = beta; SD = standard error; OR = odds ratio; CI = confidence interval.

\*  $p < .05$

*Research Hypothesis 1*

Perceived susceptibility and severity of HBV infection will be positively associated with (a) HBV screening and (b) HBV vaccination

The results of logistic regression analyses conducted to examine the relationship between perceived susceptibility and perceived severity to screening behavior is shown in Table 4.10. In the bivariate analysis, perceived susceptibility was not associated with screening. In addition, the perception that *my life would change if I had hepatitis B* was significantly associated with screening, but the perception that *people infected with hepatitis B will die from liver cancer* was not associated with screening. When adjusted for covariates found to have significant bivariate relationships with screening at  $p < .10$ , the perception that hepatitis B is life changing remained significant. That is, those who agreed were less likely to be screened than other participants.

Table 4.10

*Relationship of Perceived Susceptibility and Severity to Screening Behavior*

Characteristic	Screened for Hepatitis B			
	Unadjusted OR <sup>a</sup>	95% CI	Adjusted OR ( <i>n</i> = 63)	95% CI
Perceived Susceptibility	1.45	(.92, 2.28)	1.44	(.85, 2.43)
My life would change if I had hepatitis B.	.19*	(.04, .90)	.17*	(.03, .93)
People infected with hepatitis B will die from liver cancer.	.70	(.25, 1.95)	2.17	(.46, 10.23)
Have some college education or more			1.33	(.38, 4.68)
Does seek preventive care			1.83	(.56, 5.95)
English proficiency			1.93	(.69, 5.36)

Note: OR = odds ratio; CI = confidence interval. Reference groups are: never attended-HS graduate/GED; does not seek preventive care.

<sup>a</sup> perceived susceptibility (*n* = 70); my life would change if I had hepatitis B (*n* = 69); people infected with hepatitis B will die from liver cancer (*n* = 65).

\**p* < .05 according to the Wald test of significance.

Table 4.11 presents results from the bivariate and multivariate logistic regression analyses of the relationship of perceived susceptibility and perceived severity to vaccination behavior. In the unadjusted and adjusted models, perceived susceptibility and the perceived severity items (i.e., *my life would change if I had hepatitis B* and *people infected with hepatitis B will die from liver cancer*) were found to have no association with vaccination. English proficiency remained positively associated with vaccination after adjusting for covariates.

Table 4.11  
*Relationship of Perceived Susceptibility and Severity to Vaccination Behavior*

Characteristic	Vaccinated for Hepatitis B			
	Unadjusted <i>OR</i> <sup>a</sup>	95% CI	Adjusted <i>OR</i> ( <i>n</i> = 60)	95% CI
Perceived Susceptibility	.68	(.42, 1.11)	.69	(.40, 1.18)
My life would change if I had hepatitis B.	.89	(.26, 3.03)	.59	(.15, 2.23)
People infected with hepatitis B will die from liver cancer.	.79	(.28, 2.25)	3.19	(.64, 15.83)
English proficiency			3.58*	(1.32, 9.68)

Note: *OR* = odds ratio; CI = confidence interval.

<sup>a</sup> perceived susceptibility (*n* = 66); my life would change if I had hepatitis B (*n* = 66); people infected with hepatitis B will die from liver cancer (*n* = 61).

\**p* < .05 according to the Wald test of significance.

In summary, the results did not support hypothesis 1. In terms of screening, the perception that my life would change was significantly associated with having been screened. Furthermore, only language was a significantly associated with having been vaccinated for hepatitis B infection.

### *Research Hypothesis 2*

Perceived benefits of obtaining HBV screening and vaccination will be positively associated with (a) HBV screening and (b) HBV vaccination

Results from logistic regression analyses of the relationship of perceived benefits to screening are shown in Table 4.12. In both bivariate and multivariate analyses, perceived benefits were not significantly associated with hepatitis B screening.

Table 4.12  
*Relationship of Perceived Benefits to Screening Behavior*

Characteristic	Screened for Hepatitis B ( <i>n</i> = 71)			
	Unadjusted <i>OR</i>	95% CI	Adjusted <i>OR</i>	95% CI
Perceived Benefits	.73	(.31, 1.70)	.82	(.33, 2.03)
Have some college education or more			1.66	(.53, 5.14)
Does seek preventive care			2.25	(.82, 6.19)
English proficiency			1.43	(.69, 2.96)

Note: *OR* = odds ratio; CI = confidence interval. Reference groups are: never attended-HS graduate/GED; does not seek preventive care.

Table 4.13 shows the logistic regression analyses for the relationship of perceived benefits to vaccination behavior. Bivariate analysis showed that perceived benefits were not associated with vaccination. The relationship of perceived benefits and vaccination was also non-significant in the multiple logistic regression analysis. English proficiency was positively associated with vaccination for hepatitis B.

Table 4.13  
*Relationship of Perceived Benefits to Vaccination Behavior*

Characteristic	Vaccinated for Hepatitis B ( <i>n</i> = 67)			
	Unadjusted <i>OR</i>	95% CI	Adjusted <i>OR</i>	95% CI
Perceived Benefits	.79	(.31, 2.04)	1.11	(.40, 3.06)
English proficiency			2.18*	(1.07, 4.45)

Note: *OR* = odds ratio; CI = confidence interval.

\**p* < .05 according to the Wald test of significance.

In summary, the results of the test of hypothesis 2 showed that perceived benefits were not significantly associated with screening; thus, the findings do not support the hypothesis that perceived benefits of obtaining HBV screening is positively associated with having been screened. Furthermore, perceived benefits

were not associated with vaccination in either the bivariate or multivariate models; therefore, the findings do not support hypothesis 2 for vaccination behavior. Similar to hypothesis 1, language (i.e., English proficiency) remains an important factor for hepatitis B vaccination when included in the multivariate model.

### *Research Hypothesis 3*

Perceived barriers to obtaining HBV screening and vaccination will be negatively associated with (a) HBV screening and (b) HBV vaccination

The results of the bivariate and multivariate logistic regression analyses conducted to examine the relationship of perceived barriers and screening behavior are presented in Table 4.14. Bivariate analysis showed that perceived barriers were negatively associated with screening, meaning, participants with greater perceived barriers were less likely to be screened. In the multivariate analysis model, perceived barriers were no longer associated with screening.

Table 4.14  
*Relationship of Perceived Barriers to Screening Behavior*

Characteristic	Screened for Hepatitis B ( <i>n</i> = 71)			
	Unadjusted <i>OR</i>	95% CI	Adjusted <i>OR</i>	95% CI
Perceived Barriers	.50*	(.26, .96)	.63	(.29, 1.37)
Have some college education or more			1.48	(.47, 4.69)
Does seek preventive care			2.14	(.77, 5.97)
English proficiency			1.22	(.56, 2.66)

Note: *OR* = odds ratio; CI = confidence interval. Reference groups are: never attended-HS graduate/GED; does not seek preventive care.

\**p* < .05 according to the Wald test of significance.

The bivariate and multivariate logistical regression analyses for the relationship of perceived barriers and vaccination behavior are shown in Table 4.15. Bivariate analysis results showed that perceived barriers were significantly associated with vaccination behavior. Participants with greater perceived barriers were less likely to have been vaccinated. After adjusting for covariates in the multivariate model, perceived barriers were no longer significantly associated with vaccination. English proficiency was also found to have no association with vaccination behavior in the multivariate model.

Table 4.15  
*Relationship of Perceived Barriers to Vaccination Behavior*

Characteristic	Vaccinated for Hepatitis B ( <i>n</i> = 67)			
	Unadjusted <i>OR</i>	95% CI	Adjusted <i>OR</i>	95% CI
Perceived Barriers	.42*	(.20, .88)	.54	(.23, 1.23)
English proficiency			1.62	(.75, 3.49)

Note: *OR* = odds ratio; CI = confidence interval.

\**p* < .05 according to the Wald test of significance.

In summary, perceived barriers were not significantly associated with obtaining HBV screening or vaccination; therefore, the findings do not provide support for hypothesis 3. Finally, in contrast to the other two hypotheses, the results of this hypothesis test showed that English proficiency was not associated with vaccination.

#### Qualitative Data: Key Informant and In-depth Interviews

First, qualitative results from interviews with key informants are provided. Then, the results from the qualitative questions on hepatitis B and liver cancer from the in-depth interviews are presented.



## Key Informant Interview Findings

### *Hepatitis B Knowledge*

The key informant interviews revealed that knowledge of hepatitis B in the Hmong community is low. Most key informants believed that, in general, Hmong people would not know or have a very good understanding of what hepatitis B is. A few of the key informants remarked that they, themselves, do not know about hepatitis B, and a couple of key informants had also mistaken hepatitis B with other viral hepatitis, such as hepatitis A. In contrast, a few of the key informants believed that Hmong people *would* know about hepatitis B because of the high infection rates among the Hmong, but remarked that they were uncertain about Hmong people's depth of knowledge about the disease.

Results about Hmong people's knowledge on hepatitis B transmission were similar to their general knowledge about the disease. Some key informants stated that Hmong people would know that hepatitis B is hereditary and is transmitted through blood. Misconceptions about routes of transmission were also discussed. For example, one key informant said that she had heard Hmong people say that touching doorknobs or sitting on a chair where someone infected sat could spread the disease.

Most key informants thought that Hmong people would have little knowledge about testing and vaccinating for hepatitis B. Reasons for not getting tested or vaccinated included not knowing why they would need to get tested in the first place and that they needed to actually ask their health care provider for the test. Some key informants discussed that Hmong people are open to getting vaccinated because they

are familiar with immunizations for various reasons such as, having to get immunized to come to the U.S. and having their children immunized for school.

As for treating hepatitis B, most key informants believed that Hmong people would not know how the illness is treated by Western medicine. Moreover, they believed that Hmong people would use traditional medicine to treat their condition before seeking Western medicine. Interestingly, a few key informants believed that there are traditional herbal remedies that can cure hepatitis B, as illustrated in the following quote from a male key informant:

Our Hmong people are very concerned about this. Back then, we had Hmong herbs that we could give to people and it healed them. However, after fleeing to this country, we do not have it anymore. So if we have it sent from our old country, it is very difficult to.

### *Liver Cancer Knowledge*

Key informants revealed that Hmong people's knowledge about liver cancer was similar to their knowledge of hepatitis B. Some key informants, themselves, did not know what caused liver cancer. Not having personal experiences with liver cancer was a reason for the lack of knowledge about the disease and its causes. Other key informants thought that Hmong people would understand that liver cancer was caused by alcohol. Other causes relayed were related to bad food or water, smoking, and exposure to chemicals from farming, as described by one male key informant:

I don't think that they know. They might think that due to, you know, when they were in the camp and they share the same water source. They may think that uh in locally here, maybe uh they because they socialize a

lot, they eat a lot of food together and and when family cook; they cook for 100, 200 people and if their fam- if they cook uh the food preparer happen to have it then I get it. Uh they feel that way, but I don't think they know all the detail like we do.

As for the treatment of liver cancer, key informants thought that most Hmong people would not know how liver cancer is treated by Western medicine. Others stated that people would know that chemotherapy or a liver transplant would be treatment options. The use of traditional medicine was also mentioned, in that some Hmong people would seek the help of shamans and/or use herbal remedies to cleanse the liver. However, most key informants believed that there were no traditional methods to treat liver cancer. The shamans interviewed in this study also remarked that cancer is a disease that they cannot cure.

### In-Depth Interview Findings

In general, the in-depth interviews revealed very few barriers to hepatitis B screening and vaccination. Within each topic (screening experience and vaccination experience), themes and subthemes emerged about the difficulty and ease of obtaining the hepatitis B test and vaccination for the virus. In addition, participants discussed their motivations to get screened and vaccinated. The themes and subthemes for in-depth interviews are listed in Table 4.16 and described further below.

Table 4.16  
*Themes and Subthemes from In-Depth Interviews*

<i>Topic</i>	<i>Theme</i>	<i>Subtheme<sup>a</sup></i>
Hepatitis B Screening	Difficult	Lack of Knowledge Nothing
	Easy	Provider Required Convenience Nothing
Hepatitis B Vaccination	Difficult	Nothing
	Easy	Required Convenience Family Nothing
Understanding of Hepatitis B	Name of Disease Cause Condition Seriousness Disease Inside Body Affect Body & Mind Fear	
Liver Cancer	Death Sickness Feelings	
Causes & Symptoms of Liver Cancer	Causes	Lack of Knowledge Alcohol Hepatitis Smoking
	Symptoms	
Family & Friends Experiences with Liver Cancer	Death Sickness Early Detection & Treatment Feelings Effects on Others	

Note: <sup>a</sup>Subthemes were identified for only some themes and are listed accordingly.

### *Screening Experience*

Of those participants who reported to have been tested for hepatitis B, most did not find the testing process difficult. However, some participants reported that not knowing what was involved in the testing process or why it was necessary or important made it difficult to get tested. For example:

Nobody explains to you how it's, you know, how the process gonna go. So, just make you feel uncomfortable and uh, you know, and feeling "don't want to go to get the exam," cause you don't know what things to expect. – Female in her 30s

Most participants cited that the screening process for hepatitis B was convenient, thus getting screened was easy.

Um when you see a provider and they do it right away at that time. And we don't have to go back and forth. [chuckle]. But for me, it happened, the exam was at work. – Female in her 50s

Other commonly cited factors that made the testing process easy included being recommended by a provider; the desire to know their hepatitis B status; and being required to get tested for employment, school, or travel.

Well, for that it was – doctor was like, you need to get it tested. So, it was like, okay, [laughter] I'll get it tested. So, I say, because she suggested it that I got it done, so. So, that was easy, 'cause then, she referred you to that clinic and you just go and do it. – Female in her 20s

Just wanting to know if I had it, so that is why I did it. If you have it, then you know how to take care of yourself. – Female in her 50s

Well I had to get it for the job that I was applying for, um because I didn't have records of me getting it when I was a child and so I had to get...the series as an adult...because I was working for a hospital and so

they wanted to make sure. So, I guess, I really didn't have a choice, I just did it. – Female in her 30s

### *Vaccination Experience*

Participants who reported having been vaccinated for hepatitis B also tended not to find the vaccination process difficult. Participants commonly mentioned that being required to get vaccinated, the convenience of the vaccination process, and family motivation made it easy to get vaccinated for hepatitis B. More specifically, some participants, especially younger participants, reported that they were required to get vaccinated for employment or school. Participants also remarked that getting the vaccination was fairly easy or quick and that the services were accessible. Furthermore, other participants discussed that family was a motivator to get vaccinated because family members either took participants to get vaccinated or family members were also vaccinated at the same time, as the following quote illustrates:

What made it easy was, uh, the whole family went. Oh yeah, a lot of comfort there. Well, everybody else got vaccinated, too, so that made it easy. – Male in his 20s

### The Meaning of Hepatitis B

The findings below describe participants' cultural concept of hepatitis. Questions about the meaning of hepatitis B were asked to only those who reported being positive for HBV infection (n = 7, five women and 2 men).

### *Name of Disease*

Most participants with HBV infection did not have a thorough understanding of their illness or what to call their illness in Hmong. One female participant described hepatitis B as *mob ntshav daj* [means a disease that makes your blood yellow], while other participants reported that they did not know.

### *Cause of Disease*

Roughly half of these participants knew what caused their illness, most of whom thought they were probably infected at birth. The other participants were unclear about the cause of their illness and gave vague responses, such as:

I think it's from, like, bad water... – Female in her 20s

I don't know...I've never really looked into it. – Female in her 30s

### *Condition Progression*

Only one participant (a man in his 30s) had developed chronic hepatitis B and was able to speak on the progression of his illness. The participant's condition at the time of the interview was poor. He reported being sick often and revealed that he was not employed, thus, did not have health insurance for him or his family, which made it difficult to medically manage his illness.

I think it should get better once I get on the hepatitis medication. But since, uh, I haven't got on it yet, um, I don't think it's gonna get any better until I get on the medication because there's a hepatitis B medication that you can take that will bring the, uh, the virus down...

Because the, uh, the medication is expensive, like with insurance it's – you're running about \$100.00. Without it, it's about \$700.00...for a month's supply.

Other participants did not know how their condition would progress or if it would become chronic at all.

So, I won't, they don't know for sure. They, it could trigger in my body to have be worse, it could trigger my... I could never ever have it. It could be fine. Yeah! I could be fine, no sick – no symptoms. Or my body could trigger and I could have it. – Female in her 20s

### *Seriousness of Disease*

Most participants with HBV infection believed that their illness was not serious and did not seem immediately worried about the illness. In contrast, one participant believed that his condition was quite serious.

I think it's really serious, and...I think that there needs to be a little bit more education out there on making sure that you get tested and screened for it because it's, um, a liver isn't an easy organ to come by and...and waiting lists are forever... – Male in his 30s

### *Disease Inside Body*

Most of the women who had hepatitis B were not able to describe what they think hepatitis B does inside their body. Many of them stated that they did not know and, by most of their responses, did not seem concerned about the disease. A few guessed that it had something to do with the liver and that the virus causes the liver to function improperly. For example:



Honestly, I don't know. The liver...Um, like a liver failure?...I think it just doesn't filter, help you filter your body. As it slows down the liver.  
– Female in her 20s

One female participant, whose hepatitis B was inactive at the time of the interview, discussed her understanding of what the virus is doing inside her body and the precautions she takes to not transmit the virus to others:

Right now, it's just lying dormant. We carry it and that's all...we have the ability to infect other people, so you try not to, you know, share food, so you don't try to chew food and give it to your baby, um, you know, protect yourself when you have sexual intercourse. – Female in her 30s

### *Affect Body and Mind*

Some participants reported that they did not think much about the disease and stated the virus did not affect their mind or body. For those participants who had a better understanding of hepatitis B, they were able to describe how the virus affects them mentally, emotionally, and physically as illustrated by the following quotes:

Hepatitis B is like a...it's an actual disease that could potentially lead to the end of your life, um, from my understanding, you know, depending on how bad it can get...how quickly you can catch it and how quickly you can...put in place preventive measures and just knowing that and, you know, it takes, it can really, you know, have a spiral effect and make you depressed. It makes you depressed and when you're depressed, you're not thinking clearly, and it makes you unresponsive to wanting to do anything. You lose complete motivation...then you start to lack self-esteem and, I think, it just kinda sort of really affects you because...your mindset plays a big role in, in how you treat your body. How you, um, get help or look for help or how you know, the decisions that you make...if you're depressed and you are convinced that you've go

hepatitis B and it's the end, why are you gonna go for help?...So I think it takes a, it's a huge emotional toll. – Female in her 30s

For me, it doesn't really affect my mind as much. Body-wise, is a lot of, uh, weight gain because of water, fluids, just build-up fluids from your, your liver functions aren't working properly, so you're not filtering out the water. So, it, it needs somewhere to go and it...it just stays in your body. – Male in his 30s

### *Fear*

Participants revealed that what they most feared about hepatitis B is getting cancer, suffering, and dying. The following quote illustrates these fears:

That it could be nothing one day and then it could be something the next day...there's a lot of suffering. I think there's a lot of pain and suffering that's involved in it. – Female in her 30s

In addition, participants discussed that the cost of treatment and the effects of cancer treatments on their bodies were the things they most feared about treating their illness. One female participant reported that she had no fears, stating that she does not worry about the disease and has forgotten to be afraid. With a different perspective, the participant with chronic hepatitis B discussed his fears:

I don't really have fear of the treatment. It's the end result that's mostly feared...the end result of the disease. – Male in his 30s

### Liver Cancer Beliefs

When asked what it means when hearing the words liver cancer, participants described various beliefs about the illness. Participants tended to have fatalistic beliefs about liver cancer. For example, liver cancer signified death or incurable disease. Other participants described liver cancer in more technical terms, such as a tumor or deformation of cells. The following are themes that emerged from the interviews that reveal participants' beliefs about liver cancer.

#### *Death*

Participants commonly cited *death* when hearing the words liver cancer. To most participants, getting liver cancer was a *death sentence*. Death was mentioned in combination with other thoughts, such as incurable disease and fear of disease. The following quotes illustrate this reaction:

That means [sigh] there's no hope there. You're done. You're done. –  
Female in her 40s

If you hear that, then prepare to die. – Female in her 50s

Suffering and death. – Female in her 30s

#### *Sickness*

Participants associated liver cancer with having a sickness or illness that is incurable. Several participants stated that liver cancer is a hard illness to treat and that a person diagnosed with liver cancer endures a great amount of suffering and eventually death.

### *Feelings*

Participants expressed a myriad of feelings when describing liver cancer. Most people expressed fear of the disease, worry, and loss of hope. Other feelings of depression and disappointment also surfaced.

Liver cancer, *poob siab nthav* [means to become completely shocked or to be in despair]. – Male in his 60s

Liver cancer, people will die very fast. It is scary. Yeah and *nhraib* [means afraid] because the liver is soft and, is, even if treated it doesn't really work like other tissues. So if it's liver cancer then *tag kev cia siab* [means to completely lose faith, confidence, to be very sad] for me...  
– Female in her 40s

One woman believed that liver cancer was more severe than breast cancer, as described in the following quote:

I would be more afraid of, of having liver cancer. Like with breast cancer...my mindset would be, "Okay, I need to get treated. I would – I need to do this." And if somebody told me – if the doctor told me I had liver cancer, my first thought would be, "Oh, my god. I'm gonna die." –  
Female in her 30s

### Causes and Symptoms of Liver Cancer

To gain an understanding of what participants knew about liver cancer, questions about the causes and symptoms of liver cancer were asked. Responses varied from alcohol to biological causes; however, the majority of participants lacked knowledge of the causes and symptoms of liver cancer. The following are the major subthemes that emerged.

### *Alcohol*

Alcohol was the most frequently identified cause of liver cancer. Almost all of the participants who gave this response were under the age of 40. Alcohol was mentioned along with other causes, such as smoking, drug use, and/or other diseases.

The cause is from drinking A LOT. Use of drugs. I think drinking, drinking a lot of alcohol will make your liver bad. – Female in her 50s

I don't really know actually besides alcoholism. – Male in his 20s

I know that drinking can cause it, or just other, um, poisonous substance that you, that somehow you ingest so it becomes part of our body that your, your system has to filter out and causes...I guess anything that would cause your liver to react abnormally to it, and then causing abnormal growth or causing psoriasis, or anything that would cause, I guess, a cell deformation. – Male in his 20s

Um, I don't know, also...if maybe one, you eat something that wasn't right and it made your liver, lungs, organs react, but that is just what us Hmong think. Like you eat something raw that caused you to be sick, but as far as I know drinking alcohol will burn the liver and lungs. Eating certain medicines [...] but I don't know also. I had an uncle whose liver and lungs, because he smokes too, his liver and lungs dried up, his lungs dried up and his liver was still okay, but his lungs dried up. So it deteriorated. – Male in his 50s

### *Hepatitis*

Some participants knew that liver cancer was associated with the hepatitis virus (i.e., hepatitis B or hepatitis C). Younger participants were able to give more technical responses about the causes, and they were more aware that hepatitis B could lead to liver cancer than the older participants. For example:

I think I have a good understanding of that...like hepatitis B is, um, in the Hmong population it's like the number one cause of liver

cancer...Hmong people have the highest rates of liver cancer in the U.S.  
– Female in her 20s

I know hepatitis B could lead to it. I guess if you get, uh, a virus that attacks your body and it attacks up to your liver [pause] because, especially your liver, um it protects your body and without it, you'd die.  
– Male in his 30s

Well some people have it from genetics...In the family, it runs in the family. Others, you can catch it from others. – Female in her 30s

### *Smoking*

Some participants incorrectly cited smoking as a cause of liver cancer.

Moreover, a few participants confused liver cancer with lung cancer, as the following quotes illustrate:

The cause of the, uh liver cancer, number one, uh, well. There's multiple, but uh, what I know of is smoking is one of them. And symptom is um. Sometimes you have bad cough, you know like that, like that could be one of them. – Male in his 20s

I don't know either, but I see on TV they broadcast about it, the reason why people have liver cancer is because [...] then whoever, whoever inhales it [secondhand smoke?] then it causes them to have liver cancer. Now there are a lot of people with liver cancer, it's because of that. Yeah, the young people who don't even smoke, they have liver cancer cause they inhale the [...] air. – Female in her 40s

As far as I know [clears throat], I don't know clearly, but going to school [...] maybe it's an effect from smoking. For example, if it's a person who doesn't smoke, then I don't know. – Male in his 30s

### *Other Causes*

Other responses about the causes of liver cancer were wide-ranging and no major themes emerged, but are interesting and worth mentioning. Older participants tended to relate the causes of liver cancer to eating bad food, drinking bad water, or environmental factors, such as chemicals that one might be exposed to in farming.

When us Hmong lived in the other country we ate bad food and it caused problems for the liver. In addition, drinking alcohol caused liver disease and eating dirty things that were not clean causes liver disease.

– Male in his 50s

Right now, if we were to talk about our Hmong people, that is what most people have, the sickness with their liver. That is what you have seen and heard of. For most people who are sick is from their liver, liver cancer... But...most of them believe that it is because they garden. So, it is caused by the chemicals. But, I don't know if it is because of that...I think it is from the chemicals from the gardening because mostly they are the farmers. The Hmong farmers. – Female in her 50s

Another interesting response was about how emotional distress can contribute to liver cancer. The Hmong tend to associate emotions with the liver rather than heart, which is more common among Westerners (Culhane-Pera & Xiong, 2003). However, only a few participants associated liver cancer with emotional distress. For example:

When you are sick then, you will be worried only. As far as I know, I would just be stressed. I would be very stressed. I would be very stressed and it will make me *mob siab* [means pained liver] As far as what I have seen it is from stress and then they will get liver disease.

– Female in her 60s

I don't know. From *nyuaj siab* [means troubled liver; feelings of depression]. *Nyuaj siab, mob mob lub siab* [means troubled liver and pained liver; to be depressed, stressed, or worried and then causing your liver to get sick] then you just get sick with it. I think that if they are

*nyuab siab, mob siab* then...they can't help themselves and then they get really sick going forward, right? – Female in her 50s

### *Symptoms of Liver Cancer*

Some participants were able to correctly identify some of the physical symptoms of chronic hepatitis B and liver damage, such as jaundice (yellowing of the skin and whites of the eyes), fatigue, and water retention in the stomach. The following quotes demonstrate this knowledge:

Well, a person who is getting sick before they are sick that person is white and clear, but when they are sick they are bruised and darker. Even if they are skinny or fat their face will get darker and that will tell you that person has liver disease. – Male in his 50s

It made them *dlaaj ntseg* [means yellow skin] and their stomach was very bloated. – Female in her 50s

Um symptoms, well like you, my grandfather had it and he couldn't urinate and it just built up inside of him so they had to release it. Uh, I guess fatigued because your body's trying to fight to get rid of the virus but it can't and um things that begin shutting down. I mean the liver, you know, is contaminated, your organs start shutting down, so you die. – Male in his 30s

...I think some of the symptoms, like, like, early on, you know if you're a little bit infected, I don't think you'll show anything, but it's only when, you know, you're at the late stages of the liver cancer, you'll have like, you can have a big belly filled with water and stuff and fluid or you could have yellowing of your skin and eyes. – Female in her 20s



## Liver Cancer Experience of Friends and Family

Nearly half of the participants reported that they knew of someone, such as family and/or friends, who had liver cancer. Participants were asked what they knew about the persons' experiences with liver cancer. Several themes emerged, including death, sickness, feelings, early detection and treatment, and effect of illness on others. The following sections describe those experiences.

### *Death*

Participants who had family members and/or friends who had liver cancer stated that the illness took over the person quickly, and it seemed that they *just became sick and then died*. Below is a description given by a man in his 50s about his personal experience with liver cancer.

Participant: I had a cousin who had live cancer. Before he was sick he wasn't black, but when he got sick, he got darker and then he died...The ones that are sick like that, they are different from before. They um, the face changes right away, the skin changes right away. And, also they will be sick like that and will die really soon.

Interviewer: What do you think are their experiences when they are sick with this?

Participant: Their experiences, the medicine they take won't help them, the doctors won't be able to help the liver...

### *Sickness*

Participants described that their family and friends who had liver cancer *suffered miserably*. The illness was described as a painful condition.

Well he, he suffered for a whole year. The last month was probably the worst because they tried a liver transplant and um they did the transplant, but the body rejected it. He got worse and went into a coma, so. – Male in his 30s

It's very, uh, miserable. I think it's very sad. Um, in most time – to me, I think by knowing that you have it, you know, that already kill you, you know, so. – Male in his 40s

### *Early Detection & Treatment*

Some participants reported that people they knew who had liver cancer waited too long to get diagnosed and treated. One participant described that a person she knew who was ill refused a liver transplant because of cultural reasons. Another participant described the use of traditional healing methods (i.e., shaman) to treat liver cancer.

They're a very traditional family, they refuse, um, Western medicine. And, uh, the doctor, [pause] they were going to give him a transplant but they refused to because he needs to die with all his organs. So, he could've lived, like, six more months with his family, if they did the eh-, the transplant, but [pause], um, he's like, "No. Six more months? That's not gonna do it." – Female in her 20s

It was very tough. Like, I didn't know how to handle it and I think that they always tried using, like, shamanism first because they felt it was a spiritual problem and then after that, like, you know, I guess, yeah, it was – it would always be too late cause no one really thinks about it. – Female in her 20s

### *Feelings*

Participants commonly described that they felt worried, scared, and sad for the people they knew who had liver cancer. For example, one participant remarked:

It makes them sad for the rest of their life. You, yourself, are sad with them because um [pause] as for myself, you have never seen that kind of disease before, where it's quick and is like that, so when someone has that disease you uh are sad with them or you're sad yourself. – Female in her 50s

### *Effects on Others*

Participants also described the effect of the illness on others. They described the illness as *taking a toll on families* and like *nothing that they have ever experienced* because liver cancer was not a disease that Hmong people knew about in the old country (i.e., Laos).

It was depressing. Um [pause] it made the whole family and the whole clan worry a lot. Yeah, they were in, in pain. – Male in his 20s

### Summary of Qualitative Findings

Results from the qualitative data indicated that study participants had low knowledge of hepatitis B and liver cancer, even among participants who reported to be positive for HBV infection. Interestingly, participants experienced few barriers to screening and vaccination. Although many participants were able to correctly identify causes of liver cancer, misconceptions about the causes were still apparent for some.

## CHAPTER 5. DISCUSSION AND CONCLUSIONS

This chapter discusses the results of the study, followed by the study's strengths and limitations. Next, suggestions for future research are provided. Finally, the study conclusion is presented.

### Discussion

#### *Knowledge of Hepatitis B*

The findings of this study indicate that most study participants had heard of the hepatitis B virus; however, a more comprehensive knowledge of the disease among participants was lacking. In-depth interviews revealed that most participants did not know what hepatitis B is and how it is caused, transmitted, or prevented. Although many participants correctly identified most of the routes of HBV transmission, there were still large gaps in knowledge. For example, almost 40% of participants were unaware that sexual intercourse was a route of HBV transmission, and 41% did not know that sharing a toothbrush could spread the virus. In addition, more than half (57%) did not know that the virus is not transmitted through coughing. Hepatitis B knowledge among participants was slightly higher compared to that reported in a study with Cambodians in Seattle, WA, which showed that only 46% of respondents in that study knew that HBV could be spread through sexual intercourse, 53% knew that HBV could be spread by sharing toothbrushes, and only 32% knew that the virus

could not be spread by coughing (Taylor et al., 2009). Moreover, the results of this study were similar to the findings of another study conducted with Vietnamese in Seattle, WA (Taylor et al., 2000). The lack of HBV knowledge among individuals who may be HBV positive and not know their status could potentially put those who are susceptible for contracting the disease at risk.

Although knowledge of HBV was not associated with screening or vaccination behavior, qualitative findings indicated that participants do not have a comprehensive understanding about the disease. This lack of comprehensive understanding was also common among those who reported being HBV positive. Many participants did not know what to call the disease in Hmong. Some hepatitis B positive participants did not know how they got the HBV infection, while others mentioned that they contracted the virus from their infected mothers at birth, which is a common route of transmission in this population (Gjerdengen & Lor, 1997; Hurie et al., 1992; Mahoney et al., 1995).

Findings show that, in general, Hmong do not understand that hepatitis B is highly preventable, is incurable if they become infected, and that infection can lead to liver disease or liver cancer. These findings are similar to other studies with the Hmong (Butler et al., 2005, Gjerdengen & Lor, 1997; Hurie et al., 1992; Vryheid, 2001). Less than half of the participants knew that HBV was incurable (46%), which was higher than previous studies with other Asian populations, such as Vietnamese (22%) (Taylor et al., 2000) and Chinese (18%) (Thompson et al., 2002). A potential factor that might influence this perception is the belief among traditional healers that

there is a cure for hepatitis B. This could be a cause for concern for those who are chronically infected and need appropriate medical care. In one review article (Tran, 2009), a physician found that the use of herbal remedies was very high (80%) in her medical practice among patients who were diagnosed with hepatitis B. Another study on chronic hepatitis B awareness among Asian Americans showed that nearly 20% of respondents believed that herbal medications were better alternatives to prescription drugs to treat hepatitis B (Upadhyaya, Chang, Davis, Conti, Salinas-Garcia, & Tang, 2010). This is important information for physicians with patients who are considered high risk for HBV infection to 1) recommend hepatitis B testing, and 2) question patients if herbal remedies are used and how often they are used to treat a patient's hepatitis B condition.

These findings are important indicators that greater hepatitis B awareness through education or other prevention strategies is needed in this and perhaps other Southeast Asian populations of similar cultural, historical, and migration experiences (e.g., Mienh, Burmese, and Cambodian). Greater hepatitis B awareness is particularly important for pregnant women with chronic HBV who may not be aware of their infection status and can pass it on to their unborn child (CDC, 2005). Having a better understanding of their illness might encourage women to ask their providers for a liver test and the appropriate treatment to reduce their risk of liver damage. Awareness should also be heightened among physicians who care for patients that are high risk or are from hepatitis B endemic areas, so that opportunities for screening or vaccination are not missed. In addition, hepatitis B is not recognized as a public health problem

in the U.S.; therefore, there are many challenges to increasing screening and vaccination among the general population and, more specifically, among members of specific at-risk populations (IOM, 2010). Recently, the IOM (2010) concluded that the current approach to the prevention of viral hepatitis (i.e., hepatitis B and hepatitis C) is not working. The committee recommended that the CDC conduct a comprehensive evaluation of the national hepatitis B and hepatitis C health surveillance system to provide accurate data to policy makers in order to allocate sufficient resources to viral hepatitis prevention and control programs (IOM, 2010). Furthermore, the committee called for a coordinated effort between health care and public health professionals, the federal government, and the general population to address and eliminate this health disparity.

#### *Hepatitis B Screening and Vaccination Behavior*

As noted above, nearly all of the participants had heard of hepatitis B, yet screening and vaccination rates were low. This study found that although half of the participants in the study had been screened or vaccinated, just as many had not or did not know if they had been screened or vaccinated. Furthermore, less than 10% of the participants reported being positive for HBV infection, which was much lower than that reported in other studies with the Hmong (Gjerdengen & Lor, 1997; Hurie et al., 1992). This finding suggests that there might be underreporting of people who may be HBV positive. A limitation of this study in assessing screening and vaccination behavior in this population is that self-reporting might be flawed due to inaccurate

participant recall, desirability response bias, or confusion about other types of testing and vaccination (e.g., hepatitis A or tuberculosis). To address these limitations, we would have needed to examine participant's medical records or conducted serological testing, but these procedures are beyond the exploratory nature of this study. Also, to accurately determine participants' immunity to hepatitis B, a question about how many of the three hepatitis B injections participants received could have been included. The addition of this question might have also clarified the type of viral hepatitis participants received screening and vaccination for (e.g., hepatitis A or B). Furthermore, questions addressing reasons why participants did not get screened or vaccinated could further identify barriers to screening and vaccination for the Hmong.

Participants in this study reported few barriers in terms of obtaining screening or vaccination for hepatitis B infection. Qualitative data revealed that convenience of screening and vaccination; being required by an employer, school, or for travel; and personal and family motivation made it easy for most participants to get screened and vaccinated. However, the lack of knowledge about the process and/or why hepatitis B vaccination was important made it difficult for some participants to get screened and vaccinated. Quantitative analysis on this relationship could be further explored in future research.

Results also showed several factors were associated with screening and vaccination behavior in the bivariate analyses. For screening, having a college education, health insurance, seeking preventive care, having a doctor's recommendation to get screened, and English proficiency were associated with having



been screened for hepatitis B. When included in the multivariate analyses, the variables, health insurance and having a doctor's recommendation to get screened, were significantly associated with screening, but produced very wide confidence intervals; therefore, were not included in the final model. Although these variables were not significant, the relationships are worth noting and perhaps need to be further examined with a larger sample. Only English proficiency was found, in the bivariate analysis, to be associated with having been vaccinated for hepatitis B.

Having health insurance was found to be associated with having been screened for hepatitis B in the bivariate analysis, but not for having been vaccinated. Reasons for this difference are unclear, and perhaps could have something to do with one's personal time, not knowing the difference between screening and vaccination procedures (vaccination requires going back for three injections over a six month period), or participants might feel that if the screening result is negative then it is not necessary to do anything further (i.e., vaccinated). Interestingly, most participants had health insurance (83%), yet nearly half of the participants had not been screened (47%) or vaccinated (49%). Lack of health insurance has been shown to contribute to lower knowledge of HBV infection and low screening and vaccination rates (Choe et al., 2006; Ma, Shive, et al., 2007). The findings of this study indicate that there may be other factors that might play a role in the lack of screening and vaccination in this population, such as the lack of symptoms, cost of screening and vaccination or insurance co-pays, cultural beliefs, and/or a comprehensive understanding among

patients and providers about the high rates of hepatitis B and liver cancer in the Hmong.

Although the relationship between having a primary health care provider and screening and vaccination was not significantly associated, the percentage of participants with a regular health care provider (61%) was much higher compared to other studies. Shiekh et al.'s (2010) study in California showed that only 37% of Hmong had a regular health care provider. Results from this study were most similar to Coronado et al.'s (2007) findings with Chinese in Seattle, in that health insurance coverage was high and more than three-quarters of the sample had a primary health care provider, but less than half (48%) had ever been tested for hepatitis B. Studies have found that having a regular health care provider is important for quality of care, and that individuals who do not have regular health care providers are less likely to have up to date immunization records (Alessandrini et al., 2001; Baker, Dang, Ly, & Diaz, 2010; Lieu et al., 1994; Upadhyaya, 2010).

The study results also showed that only 36% of the participants had been recommended by a doctor to get tested for hepatitis B. This finding demonstrates that, even among physicians and other health care providers, there might be a lack of knowledge or awareness about hepatitis B infection in this population. Studies have shown that many Asian Americans rely on doctors' recommendations; therefore, increasing provider knowledge may lead to increased screening and vaccination rates in this population (Nguyen, Taylor, et al., 2002; Nguyen, McPhee, et al., 2007). In contrast, Upadhyaya and colleagues' (2010) study with physicians revealed that,

although most physicians in the study were aware of the high prevalence of chronic HBV among Asians, universal screening of Asian American patients was not practiced by most providers and that only 33% of respondents routinely screened all new patients of Asian descent. Findings indicate that more education among both individuals and providers is needed regarding HBV infection, prevention, transmission, and treatment.

### *Linguistic Acculturation*

English proficiency was used as a measure of linguistic acculturation and was the only variable significantly associated with vaccination in two out of the three multivariate models (hypotheses 1 and 2). In addition to having greater English proficiency, the findings also showed that participants in this study had higher education levels and a greater percentage had health insurance and a primary care provider, compared to Hmong in other studies. These findings indicate that the Hmong in Oregon are, perhaps, more acculturated than the Hmong in other communities, such as in California and Minnesota. Having been vaccinated for hepatitis B may also be influenced by broader factors that may directly or indirectly play a role in this population's vaccination behavior. For example, participants in this study may be more up-to-date on routine vaccinations because of immunization requirements for school (e.g., college). Or, having a primary health care provider may mean that participants are more aware about preventive care.

Although study participants are more acculturated compared to other Hmong populations in the U.S., interventions targeting this population should consider that levels of acculturation vary among the Hmong in Oregon. Providing linguistically appropriate materials in the Hmong language should be done out of respect and appreciation of the community, but providers and public health professionals must also take into account that some Hmong, particularly the older generation, cannot read Hmong.

Moreover, there are various ways to measure level of acculturation, such as by age, gender, education, or generation. This study used English proficiency as a measure of acculturation in analyzing the quantitative data. In addition, a comparison by age (18-39 and 40+) was used in analyzing the qualitative data. Future studies should consider exploring the other approaches mentioned above to measure level of acculturation in this population.

#### *Perceptions of Risk for Hepatitis B*

Results showed that perceived susceptibility was not associated with screening or vaccination. This finding may explain why screening and vaccination were low among study participants. Participants may not have felt they were at risk for HBV infection; therefore, did not need to take preventive measures. The findings of this study were in contrast to that of Ma, Fang et al.'s (2007) study with Vietnamese immigrants, in which they found that perceived susceptibility was positively associated with screening. Interestingly, the present results showed an inverse

relationship between beliefs that HBV infection was life changing and screening behavior. One reason for this may be that participants who perceived greater severity may be afraid to learn that they have hepatitis B; therefore, prefer not to find out test results. Some participants in the in-depth interview also remarked about this belief that it is better to not know if one is sick (e.g., diagnosis of cancer). Public health efforts to increase screening and vaccination in this population should consider how perceived susceptibility and severity might influence or motivate screening and vaccination behavior.

Findings also indicated that participants did recognize the benefits of screening and vaccination; however, perceived benefits were not associated with screening or vaccination. The reasons for this are unclear, but perhaps it could be due to the lack of personal motivation to get screened or vaccinated. One can understand the benefits of early detection and protection of transmission to others, in general, but may not translate this knowledge into action (e.g., actually getting screened/vaccinated).

Furthermore, the results showed that the relationship of perceived barriers to screening was significant in the bivariate analysis. Similarly, the relationship of perceived barriers to vaccination was also significant in the bivariate analysis. However, the relationship was not significant in the multivariate model. Factors considered as barriers in other studies were not barriers to most of the participants in this study. Most participants reported that language or location of services were not barriers to screening or vaccination. Although slightly more than three-quarters of the participants reported that they disagreed that screening is not necessary if one feels

well, qualitative data indicated that participants felt that, if one is asymptomatic, then it is not necessary to get screened.

Finally, a doctor's recommendation for screening for individuals in this population can serve as a powerful cue to action to get screened. Other cues to action (i.e., HBV positive family member and attending an HBV educational workshop), although not associated with screening or vaccination, are also important indicators for improving knowledge about the disease in the Hmong population. Results showed that nearly two-thirds had no personal experience of HBV infection, and almost all had never attended an HBV educational workshop. Public health efforts to increase awareness and screening in this population should consider these cues to motivate such behavior.

### *Knowledge of Liver Cancer*

Knowledge about liver cancer was also low among participants in this study, especially among the older generation. A range of beliefs about the disease was discussed in the in-depth interviews. Among those who had some knowledge about the disease, alcohol was commonly mentioned as a cause of liver cancer. This suggests that public health campaigns about alcohol abuse and its consequences might have been effective in raising awareness about cirrhosis of the liver among the participants in this study.

In-depth interviews also revealed misconceptions that some participants had about the disease. For example, some participants believed that drinking bad water or

eating bad food were potential causes of liver cancer. Other participants confused liver cancer with lung cancer and believed that smoking or secondhand smoke contributes to the disease. These responses demonstrate that some Hmong may be unaware of the differences between the functions of the lung and liver and about liver cancer and its relation to hepatitis B infection; therefore, greater awareness through education about the disease is needed in this population. Furthermore, studies have found that liver cancer is a significant health disparity affecting Asian Americans (Kwong et al., 2010; Miller et al., 2008; McCracken et al., 2007). In particular, Lao-Hmong Americans have the worst survival rates for liver cancer (Kwong et al., 2010). Lao-Hmong Americans are more likely to be diagnosed with liver cancer at later stages, and are least likely to receive any kind of treatment (e.g., liver transplant) compared with other Asian ethnic subgroups (Kwong et al., 2010). For these reasons, it is crucial that education and outreach targeting this population be implemented in order to improve screening rates and appropriately treat the disease. These findings also warrant further research on the knowledge and beliefs of liver cancer and barriers to treatment and care among the Hmong.

### Strengths and Limitations

Aside from the limitations discussed above, there are other limitations that need to be addressed. Given the exploratory nature of this study, the non-probability sample makes it inappropriate to generalize beyond the study sample. In addition, the

small sample size limits the number of independent variables that can be included in multivariate analyses, and analyses were generally only able to detect large effects. Also, because of the small sample size, a few of the variables had to be dropped from the multivariate analyses, leaving fewer variables to include in the final multiple logistic regression models. For example, health insurance and doctor's recommendation to get screened were significantly associated with screening in the bivariate analyses and should have been included in the multivariate analyses, but the confidence intervals of these two variables were too wide in the final models to be included.

Another limitation was that, by adding hepatitis B questions to the interview guide for the larger BCC project, the number of questions that could be added was limited. Also, as discussed earlier, income and poverty may be important factors to consider when examining the health seeking behavior of Hmong women and men. This study did not measure income or poverty status. Other measures of socioeconomic status such as education and health insurance status were, however, included. Furthermore, the interview guides for the larger project were only in English. Having a translated Hmong version of the interview guides might have benefited the interviews conducted only in Hmong, assuming we could have found staff to read them.

Another challenge was that many participants, especially older participants and those who did not speak English well, found it difficult to answer Likert scale type questions. Giving an answer *in their opinion* was confusing and seemed backwards to



some participants. Even after repeated attempts to ask the questions, participants were unsure of how to answer. One suggestion that Bernal, Wooley, and Schensul (1997) recommended when using Likert scale questions with a population with low literacy is to consider using visual aids, such as a color board in order to be effective in getting a reliable response. Although this technique was not utilized in this study, future research should consider the value of this technique. In addition, further research is needed to establish reliable Likert scale questions that work well with this population.

This study also had several strengths. First, the study takes advantage of the opportunity to piggyback data collection onto an NCI-funded study conducted in the Hmong community in Oregon, the BCC project. As such, the study benefits from the strengths and resources of the BCC project including, but not limited to, the Community Advisory Committee, trained bi-cultural and bi-lingual interviewers, and the ability to compensate study participants for their participation, as well as travel and childcare costs. Other strengths include using a mixed methods approach to explore this important health issue in the Hmong population. This approach has provided valuable preliminary qualitative and quantitative information about hepatitis B and liver cancer knowledge, beliefs, and screening and vaccination behaviors of Hmong living in Oregon. The research also used measures that were drawn from theory and used in previous studies, some shown to be valid and reliable in other Southeast Asian populations. Also, information gained from this study may contribute to scientific knowledge about hepatitis B and liver cancer in the Hmong community, as well as inform future research on this health issue. Finally, adequately examining beliefs and

perceptions of Hmong can provide the knowledge base to develop culturally appropriate hepatitis B and liver cancer interventions aimed at increasing hepatitis B screening and vaccination rates in the Hmong population.

### Recommendations for Future Research

Clearly, there is still more to be learned about Hmong people's beliefs and understanding of hepatitis B and liver cancer and barriers to screening and vaccination, and this study is a small step in that direction. The results of the topics explored in this study warrant further investigation to improve understanding of Hmong's knowledge and beliefs about hepatitis B and liver cancer, as well as their decision-making process around screening and vaccination. The lack of understanding about HBV infection can contribute to continued transmission, late diagnosis and treatment, and poor health outcomes (IOM, 2010). This study underscores the importance of designing culturally and linguistically appropriate interventions to improve HBV screening and vaccination among the Hmong in Oregon, as well as a larger public health effort aimed to educate the Asian Pacific Islander population in the state of Oregon.

Future research should also examine cultural concepts of disease, such as hepatitis B and liver cancer, guided by theories or models such as the Explanatory Models Approach. Exploring how participants understand a certain health issue or disease and their experiences with that issue or disease is essential in developing

appropriate health education and prevention strategies. Moreover, future research with the Hmong should examine the development of appropriate measures to address the gaps in knowledge and identify barriers to screening for this population.

Other recommendations for future research include examining the Hmong's compliance of childhood immunizations, utilization of screening services among those who have health insurance, and the use of traditional Hmong health care practices in treating HBV infection. Studies show that certain cancers, such as liver and cervical, can be preventable with adequate immunizations (Smith, Cokkinides, Eyre, 2006); however, the Hmong are least likely among Asian ethnic groups to obtain these immunizations for their children (Bulter et al., 2005) and fail to receive adequate and timely immunizations (Baker et al., 2010). Furthermore, the current study showed that Hmong participants, despite having health insurance, underutilized hepatitis B screening and vaccination services. Health insurance alone is not enough in creating access to health care for a population that faces other barriers that affect cancer screening behaviors. Future research should examine Hmong, as well as other Asian Pacific Islander groups, that have health insurance and ways to improve immunization rates among these populations. Finally, the use of traditional health care practices such as, medicinal herbs and shamanism, to treat hepatitis B has been shown to influence screening and vaccination status (Baker et al., 2010; Butler et al., 2005; Tran, 2009; Upadhyaya et al., 2010). It would be interesting to examine the type of traditional health care practice being used, how often it is used, and its effect on patients' hepatitis B condition. Furthermore, as noted earlier, traditional healers, such

as shamans and herbalists, play important roles in Hmong's traditional health care practices and should be considered in developing hepatitis B interventions for this population.

### Conclusion

Asian Americans are affected by HBV infection and liver cancer more than any other racial and ethnic group in the U.S. (CDC, 2005; Kwong et al., 2010; Lin et al., 2007; Lok et al., 2009). Because the Asian American population is rapidly growing, hepatitis B will continue to have a devastating toll in terms of lives affected and the economic burden to the health care system (Nguyen et al., 2007; Upadhyaya et al., 2010). Screening and vaccinating for hepatitis B among Asian Americans should be a priority in public health policies and research. It is imperative to raise awareness about hepatitis B and liver cancer in the Asian American community, in particular the Hmong community, and get individuals screened. Current evidence suggests that the Hmong population face unique cultural, social, language, and health care access issues that complicate hepatitis B awareness, screening, and vaccination (Baker et al., 2010; Butler et al., 2005; Gjerdingen & Lor, 1997; Hurie et al., 1992; Sheikh, 2010;).

In conclusion, by addressing cultural and social factors that may influence the Hmong population's knowledge of hepatitis B and liver cancer and their cancer screening behavior, the current research provided a more comprehensive understanding of this important health issue. Moreover, better understanding of the perceptions of risk to HBV infection and barriers to screening and vaccination may

lead to ways of improving hepatitis B screening and vaccination behavior and ultimately, the lives of the Hmong people.

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## APPENDICES

## APPENDIX A: KEY INFORMANT INTERVIEW GUIDE QUESTIONS



## SECTION 9. HEPATITIS B AND LIVER CANCER

In addition to breast and cervical cancer screening, we are interested in better understanding what Hmong think about hepatitis B and liver cancer.

I would first like to talk to you about hepatitis B infection, in general.

9.1 How would you say or describe hepatitis B in Hmong? **[If the participant does not know what hepatitis B is, skip to intro before question 9.15.]**

9.2 How much do Hmong people know about hepatitis B? **[If the participant indicates that Hmong people do not know about hepatitis B, skip to intro before question 9.15.]**

9.2.1 In what ways does this differ for men and women?

9.2.2 For older and younger Hmong?

9.3 What are Hmong beliefs about how hepatitis B is spread?

9.3.1 In what ways does this differ for men and women?

9.3.2 For older and younger Hmong?

9.4 What are Hmong beliefs about how hepatitis B is prevented?

9.4.1 In what ways does this differ for men and women?

9.4.2 For older and younger Hmong?

- 9.5 What is Hmong people's understanding about the hepatitis B testing process?

*Probe:*

Why is that?

- 9.6 What is their understanding about who should be tested?

*Probe:*

Why is that?

- 9.7 What is their understanding about why testing is necessary?

*Probe:*

Why is that?

- 9.8 What is Hmong people's understanding about the hepatitis B vaccination? **[If the participant does not know what vaccination is, provide definition from glossary.]**

*Probe:*

Why is that?

- 9.9 What is their understanding about who should be vaccinated?

*Probe:*

Why is that?

- 9.10 What is their understanding about why vaccination is necessary?

*Probe:*

Why is that?

- 9.11 What are Hmong beliefs of how hepatitis B is treated by Western medicine?

*Probe:*

Why is that?

- 9.12 What are traditional ways of treating hepatitis B infection?

*Probes:*

Why is that?

- 9.13 What are ways that family and clan influence a person's decision to get tested for hepatitis B?

9.13.1 In what ways does this differ for men and women?

9.13.2 For older and younger Hmong?

- 9.14 What about for hepatitis B vaccination?

9.14.1 In what ways does this differ for men and women?

9.14.2 For older and younger Hmong?

Now, I want to ask you a few questions about liver cancer.

9.15 How would you say or describe liver cancer in Hmong? **[If the participant does not know what liver cancer is, provide definition from glossary.]**

9.16 What do Hmong people think causes liver cancer?

9.16.1 In what ways does this differ for men and women?

9.16.2 For older and younger Hmong?

9.17 What are Hmong beliefs about how liver cancer is treated by Western medicine?

*Probe:*

Why is that?

9.18 What are traditional ways of treating liver cancer?

*Probe:*

Why is that?

9.19 What are ways that family and clan influence a person's decision-making related to liver cancer treatment?

## APPENDIX B: IN-DEPTH INTERVIEW GUIDE QUESTIONS

**HEPATITIS B AND LIVER CANCER**

In addition to breast and cervical cancer, we would also like to learn more about hepatitis B and liver cancer. I will first ask you some general questions about hepatitis B.

The following questions are mostly yes/no questions. There are no right or wrong answers. Please answer them as best you can.

1. Have you ever heard of the hepatitis B virus?

**[Circle: Yes No Don't Know]**

2. Do you think hepatitis B causes liver cancer?

**[Circle: Yes No Don't Know]**

3. Do you think people with hepatitis B can be infected for life?

**[Circle: Yes No Don't Know]**

4. Do you think someone can die from hepatitis B?

**[Circle: Yes No Don't Know]**

5. Do you think a person infected with hepatitis B can be cured?

**[Circle: Yes No Don't Know]**

6. If someone is infected with the hepatitis B virus, but they look and feel healthy, do you think that person can spread the hepatitis B virus?

**[Circle: Yes No Don't Know]**

I will now ask you a series of questions about how hepatitis B is spread. Please answer “yes” or “no” to the following questions. Again, answer them as best you can.

7. Do you think the hepatitis B virus can be spread from person to person:

Item	Response Categories		
	Yes	No	Don't Know
7.1 By eating food prepared by the infected person?	Yes	No	Don't Know
7.2 By sharing a toothbrush with an infected person?	Yes	No	Don't Know
7.3 By eating food that has been pre-chewed by an infected person?	Yes	No	Don't Know
7.4 By sharing food plates with someone who is infected?	Yes	No	Don't Know
7.5 By being coughed on by an infected person?	Yes	No	Don't Know
7.6 By sharing razors with an infected person?	Yes	No	Don't Know
7.7 By having sexual intercourse with an infected person?	Yes	No	Don't Know
7.8 When intravenous drug users share needles with each other?	Yes	No	Don't Know
7.9 By holding hands with an infected person?	Yes	No	Don't Know
7.10 From mother to child during birth?	Yes	No	Don't Know

The next few questions are about hepatitis B screening and vaccination.

8. Have you ever been tested for hepatitis B?

[Circle: Yes No Don't Know]

[If "yes," go to 8.1]

[If "no" or "don't know," go to 9]

8.1 In getting tested for hepatitis B, what things do you feel made it difficult for you to get tested?

8.2 What things made it easy?

9. Have you ever been vaccinated for hepatitis B?

[Circle: Yes No Don't Know]

[If "yes," go to 9.1]

[If "no" or "don't know," go to 10]

9. 1 In getting vaccinated for hepatitis B, what things do you feel made it difficult for you to get vaccinated?

9.2 What things made it easy?



10. Has a doctor or other health care provider ever told you that you have hepatitis B?

[Circle: Yes

No

Don't Know]

[If "yes," go to 11]

[If "no" or "don't know," go to introduction before 12]

11. What do you call this problem (hepatitis B) in Hmong?

What do you believe is the cause of hepatitis B?

How do you think your condition will progress?

How serious is it?

What do you think hepatitis B does inside your body?

How does it affect your body and your mind?

What do you most fear about hepatitis B?

What do you most fear about the treatment?

Again, the following questions are yes/no questions. There are no right or wrong answers. Please answer them as best you can.

12. Has a doctor or other health care provider ever told you that you should be tested for hepatitis B?

**[Circle: Yes**

**No**

**Don't Know]**

13. Do you have a family member who has hepatitis B?

**[Circle: Yes**

**No**

**Don't Know]**

14. Have you attended a hepatitis B education workshop in the past?

**[Circle: Yes**

**No**

**Don't Know]**

I will now read you several statements about hepatitis B. For each statement, please indicate whether you strongly disagree, disagree, are neutral, agree, or strongly agree.

**[INTERVIEWER INSTRUCTIONS: Ask the questions and circle respondent's answer. Show the response option card to the participant when reading the following statements.]**

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
15.1 I feel that I am at high risk for hepatitis B infection.	1	2	3	4	5
15.2 I worry about getting hepatitis B.	1	2	3	4	5
15.3 I worry about getting liver cancer.	1	2	3	4	5
15.4 My life would change if I had hepatitis B.	1	2	3	4	5
15.5 People infected with hepatitis B will die from liver cancer.	1	2	3	4	5
15.6 Getting tested is an effective way to detect hepatitis B infection.	1	2	3	4	5
15.7 Getting tested prevents transmission of hepatitis B to others.	1	2	3	4	5
15.8 Getting vaccinated for hepatitis B reduces worry about liver disease.	1	2	3	4	5
15.9 Vaccination is the best way to prevent liver cancer.	1	2	3	4	5
15.10 Early detection will make it easier to treat hepatitis B infection	1	2	3	4	5



**[Instructions: Proceed to Section 8]**

20. What do you call this problem (liver cancer) in Hmong?

What do you believe is the cause of liver cancer?

How do you think your condition will progress?

How serious is it?

What do you think liver cancer does inside your body?

How does it affect your body and your mind?

What do you most fear about liver cancer?

What do you most fear about the treatment?