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Constructing a Theoretically-Based Set of Measures for Liver Cancer Control Research Studies

Annette E. Maxwell, DrPH¹, Roshan Bastani, PhD¹, Moon S. Chen Jr., PhD, MPH², Tung T. Nguyen, MD³, Susan L. Stewart, PhD³, and Vicky M. Taylor, MD, MPH⁴

¹School of Public Health and Jonsson Comprehensive Cancer Center, University of California, Los Angeles

²Department of Internal Medicine, University of California, Davis Cancer Center

³Department of Medicine, University of California, San Francisco

⁴Cancer Prevention Program, Fred Hutchinson Cancer Research Center, Seattle

Abstract

Objective—Measurement tools such as surveys assessing knowledge, attitudes and behaviors need to be theoretically consistent with interventions. The purpose of this paper is to describe the first steps in the process of constructing a theoretically-based set of measures that is currently used in three trials to reduce liver cancer disparities.

Methods—Guided by a common theoretical formulation - the Health Behavior Framework - we identified constructs relevant for liver cancer control research, compiled items from previous studies and constructed new items, and translated and pilot tested items in collaboration with members of the Vietnamese, Korean, and Hmong communities.

Results—We constructed three questionnaires in Vietnamese, Hmong and Korean language that are slightly different due to cultural and language nuances, but contain a core set of measures assessing identical constructs of the Health Behavior Framework. Initial research demonstrates that items are easily understood and that they are generally related to hepatitis B screening as expected.

Conclusions—Researchers are encouraged to follow a similar process for creating theory-based assessment tools. Measuring common theoretical constructs can advance liver cancer control and other health research by facilitating a more systematic comparison of findings across different populations and intervention strategies.

Keywords

hepatitis B virus; theory-based assessment instruments; cancer prevention; community-based research

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Corresponding Author: Annette E. Maxwell, DrPH, 650 Charles Young Dr. South, Room A2-125, CHS, Los Angeles, CA 90095-6900, Phone: (310) 794-9282, Fax: (310) 206-3566, amaxwell@ucla.edu.

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Conflict of interest statement

The authors declare that there are no conflicts of interest.

Introduction

An estimated 800,000 to 1.4 million persons in the United States have chronic hepatitis B virus infection, which can lead to liver failure, cirrhosis, and liver cancer (Weinbaum et al. 2008). Reflecting the high prevalence of chronic hepatitis B among Asians Americans, incidence and mortality of liver cancer is up to eight times higher in Asian American populations than in non-Hispanic Whites (McCracken et al. 2007). Addressing this disparity, we are currently conducting a Program Project entitled “Liver Cancer Control Interventions in Asian Americans”, with the goal of increasing hepatitis B screening. In three intervention trials, we are testing a community-level media intervention among Vietnamese, an in-home patient navigator intervention among Hmong, and a small-group discussion intervention among Korean churchgoers. All three studies are using a common set of hepatitis B-related questions to gain a better understanding of hepatitis B-related knowledge and attitudes and to assess the main outcome of the studies - self-reported hepatitis B serologic testing.

Assessment tools utilized in community-based liver cancer control studies should be able to identify high-risk behavior, and knowledge, beliefs, and barriers that may influence whether or not an individual will seek or receive hepatitis B testing. If a program to increase testing is implemented, the assessment tools should be able to capture changes in behavior and related knowledge and beliefs in order to determine the impact of the program and the pathways by which change was achieved. Moreover, employing a common set of constructs and measures across studies will build a more systematic knowledge base, because it will allow comparisons between studies in different populations and between studies testing different interventions. Although the need for theory-based assessment tools that are theoretically consistent with interventions has been stressed (Pollard et al. 2007);(Vernon et al. 2004; Mullen et al. 2006; Glanz and Steffen 2008; Ryan 2009), few studies provide a step-by-step approach on how to use a theoretical framework to create questionnaire items. In fact, a recent review of 193 research articles published in ten leading public health, medicine, and psychology journals from 2000 to 2005 found that only 69 articles (36%) used theory, and among these, nearly 70% had no or very limited descriptions of how theories were operationalized in measurement, analysis, and/or the design of interventions (Painter et al. 2008). The authors of this review suggest that “researchers are not taking full advantage of the rich potential of behavioral theory to help solve pressing health problems.”

Our Program Project is guided by the Health Behavior Framework, which is described by Bastani et al. (Bastani et al. 2009) with a focus on its utility in intervention development. The purpose of this paper is to describe the first steps in the process of constructing theoretically-driven measures for community-based research to reduce liver cancer disparities. A core set of measures assessing identical constructs of the Health Behavior Framework is currently being employed in our three intervention trials, which will yield important information on the reliability, validity, and predictive power of the measures and their underlying constructs in three separate populations and in the context of three different interventions.

Methods for creating survey items and resulting products

Use of a theoretical framework

The Health Behavior Framework (Bastani et al. 1999; Bastani et al. 2007), (see Figure 1 in (Bastani et al. 2009) was used to guide the development of interventions and assessment tools for the Program Project. This Framework incorporates constructs from many of the common theoretical formulations in health behavior including Social Cognitive Theory (Bandura 1989; Bandura 2004), the Health Belief Model (Becker and Maiman 1974), the Theory of Planned Behavior (Fishbein and Ajzen 1975; Ajzen and Madden 1986), and Social Influence Theory (Greer 1988; Lomas and Haynes 1988; Mittman et al. 1992). The Framework entails

the identification of factors fundamental to health behaviors and their antecedents and helps identify the relationship among these factors. For instance, this Framework includes important constructs such as self-efficacy (Bandura 1977; Rosenstock et al. 1988), social support (Farquhar 1978; Venters 1986), and cultural factors, all of which are individual factors that can influence health behavior and that are potentially mutable through interventions. In addition, the Framework includes individual factors that are usually immutable such as demographic characteristics and health care coverage and benefits. The Framework also acknowledges the influence of provider and health care system factors, such as provider characteristics and health care settings, and the influence of broader factors such as social norms.

Obtaining community input

Each project received input from a community advisory board and had investigators and staff from the specific Asian ethnic group that it targeted to ensure that all materials and methods used were culturally sensitive and appropriate. The Vietnamese advisory board, which includes Vietnamese American physicians and non-physician community members, has been involved in a number of prior studies (Nguyen et al. 2001; McPhee et al. 2003). The Korean advisory board is comprised of pastors, a pastor's wife, elders, and a church health program leader, and was recruited through team members' existing relationships with Korean churches. The Hmong project is partnering with the Hmong Women's Heritage Association who recommended a community advisory group of male leaders in the Hmong community to balance the strong involvement of the Hmong Women's Heritage Association in this traditionally patriarchal culture (Faderman 1998).

Conducting pilot work in the study communities

In preparation for the Program Project, we conducted some pilot surveys and informal interviews with community members and key informants to explore the communities' understanding of hepatitis B infection and testing and to assess knowledge, attitudes and behaviors regarding hepatitis B testing (McPhee et al. 2003; Butler et al. 2005; Choe et al. 2006; Bastani et al. 2007). Based on this pilot work, we developed lay term definitions of hepatitis B and questions to assess hepatitis B testing.

Lay term definitions of hepatitis B—Some community members had difficulties distinguishing hepatitis A, B and C. Some Hmong community members confused hepatitis B with TB (tuberculosis). A previous study also found that a direct translation of "hepatitis B" into Khmer (Cambodian) was meaningless, unless it was accompanied by more descriptive information (Jackson et al. 1997). We developed the following definition for the Korean project:

The disease called hepatitis B is an inflammation of the liver caused by a virus. Most infected people do not show any symptoms. Left untreated, hepatitis B could lead to more serious liver diseases.

Another definition that mentions changes in skin tone and eye color and was used in previous studies (Choe et al. 2006; Taylor et al. 2009) was preferred by our Vietnamese and Hmong partners and used in these two communities:

Hepatitis B is an inflammation of the liver caused by a viral infection. It sometimes makes the skin and eyes go yellow. People with hepatitis sometimes lose their appetite and experience nausea as well as vomiting. Unlike hepatitis A, you cannot get hepatitis B from eating food that is contaminated.

Providing these definitions before asking questions about hepatitis B may improve the accuracy of self-reported screening and related knowledge and attitudes.

Questions to assess hepatitis B testing—Some Korean and Hmong respondents reported that they were tested for hepatitis B virus. However, after receiving more information about the hepatitis B test, they changed their response and stated that they had not been tested. In a previous study from our group (Taylor et al. 2009), many Chinese Americans and Canadians reported having received hepatitis B testing during routine interval blood testing, which was not confirmed via physician validation. We recommend providing an explanation that the hepatitis B blood test is usually not done as part of a routine blood test, before asking about history of hepatitis B testing, to reduce inaccurate self-report, such as:

Have you ever had a blood test to check for hepatitis B? Keep in mind that routine blood testing usually does NOT include a hepatitis B test. Also, even though you may have received vaccination for hepatitis B, you may not have received the test.

For respondents who report receipt of hepatitis B testing, follow-up questions should be asked to assess place, time and reason for testing and, if feasible, self-report should be verified through providers (Taylor et al. 2009).

Creating a hepatitis B core questionnaire

Findings from this pilot work also formed the starting point for the creation of a hepatitis B core questionnaire for utilization in the intervention trials. While the Health Behavior Framework provided the constructs that we wanted to assess, we used several sources in the creation of questionnaire items.

First, we reviewed studies that reported correlates of hepatitis B testing in Asian populations. Table 1 summarizes selected Health Behavior Framework constructs and items that were significantly associated with hepatitis B testing in bivariate analyses ($p < .05$) in recent studies among various Asian American ethnic groups (Taylor et al. 2004;Choe et al. 2006;Bastani et al. 2007;Coronado et al. 2007;Hislop et al. 2007;Ma et al. 2007;Ma et al. 2008). As shown in Table 1, demographic characteristics (higher level of education), acculturation (greater English fluency and longer duration of residency in the U.S.), and access to care (having health insurance and a regular doctor) are generally associated with hepatitis B testing. These factors are usually considered to be immutable. Several individual-level mutable factors are also associated with hepatitis B testing in the expected direction: Asian Americans who have been tested for hepatitis B have higher levels of knowledge about hepatitis B transmission, higher perceived severity of hepatitis B infection, higher perceived susceptibility, and lower barriers to testing. Mutable factors can potentially be changed by interventions, and immutable factors may serve as moderators or may guide the targeting or tailoring of the intervention content (Bastani et al. 2009). Therefore, all of these factors should be assessed at pre- and/or post-intervention. Studies listed in Table 1 have shown the importance of communication with providers or a doctor's recommendation, which could also be addressed in interventions. The fact that the same Health Behavior Framework constructs are associated with hepatitis B testing in different studies and in different populations demonstrates that they are robust and relevant to different racial/ethnic groups. We compiled existing items from these studies.

Second, we created new items drawing on our pilot work and previous studies. Obtaining hepatitis B testing is similar to getting screened for breast, cervical or colorectal cancer in that asymptomatic individuals have to take the time to undergo a somewhat unpleasant test that could identify a serious health problem. We and others have assessed many constructs from the Health Behavior Framework in studies on breast, cervical, and colorectal cancer screening among Asian Americans and other populations (Maxwell et al. 1998; Tanjasiri and Sablan-Santos 2001; Nguyen et al. 2002; Glenn et al. 2009). Because cancer screening and hepatitis B testing are similar behaviors and the Health Behavior Framework constructs are broad (Bastani et al. 2009), many Framework constructs that apply to other types of cancer screening

also apply to hepatitis B testing (Nguyen et al. 2007). Therefore, we adapted some items that had been related to breast, cervical, and colorectal cancer screening in Asian-Americans for our studies on hepatitis B testing.

As shown in Table 2, we created a number of items to assess knowledge of hepatitis B transmission, including some incorrect items that reflect misconceptions in our populations, because this is an important secondary outcome for studies in our Program Project. We also created items to assess cultural beliefs that emerged during our pilot work, such as stigma of being infected with hepatitis B virus and the belief that blood tests can deplete the body of energy. With respect to barriers to hepatitis B testing, all projects assessed common barriers such as concern about cost of the test. In addition, each project assessed barriers that were salient in their specific community, such as concern about burdening the family if the test finds a problem in the Korean project.

Some items listed in Table 2 can be categorized into more than one construct. For example, the item “Do you think hepatitis B can cause liver cancer” could be interpreted as knowledge or as perceived severity. In this table, we have grouped only those items that refer to a specific transmission route as “knowledge of transmission” items. Many of the constructs that are listed in Table 2 can also be conceptualized as barriers to or supports for hepatitis B testing, such as having or lacking a regular source of care, receiving or not receiving a doctor’s recommendation to get screened, or not perceiving oneself to be at risk for getting hepatitis B.

When drafting this core set of items, we assessed some constructs with single items to reduce respondent burden and the cost of questionnaire administration. Research indicates that variability in comprehension of health surveys across cultural groups may be reduced by using short questions and response formats (Lee et al. 2002; Vernon et al. 2004; Johnson et al. 2006; Burgess et al. 2009). Therefore, we used simple response formats (yes/no or three point Likert scales such as *very likely*, *somewhat likely*, *not likely*). We also kept skip patterns to a minimum to facilitate questionnaire administration by trained community interviewers.

Translation and pilot testing of measures

After all projects agreed on an English language draft questionnaire, items were simultaneously translated into Korean, Vietnamese, and Hmong using a common translation protocol. A forward translation into each Asian language was reviewed and back-translated into English by at least two other bilingual staff members in each project, and passed on for comments to the respective advisory committees. Discrepancies between translations were resolved and translations for each language were finalized through discussions with the initial translator, the two reviewers, and at least two community members. In this committee forum, discussions centered on the best way to word questions to ensure that they would be understood by individuals from various regions (e.g., urban and rural), immigration histories (e.g., recent immigrant versus long-time resident), and educational backgrounds, and that items were gender- and age-appropriate. If an item could not easily be translated into one of the languages, it was first modified in English (usually simplified) and in all other languages. However, we agreed that as long as the same theoretical construct is measured in a culturally sensitive way, the exact wording of the item can be slightly different between projects.

Finally, the hepatitis B core questionnaire was pilot-tested in English and the Asian languages in 10 to 30 individuals per project, followed by debriefings to assess the length of the survey, how respondents interpreted questions, to find questions and response categories that were unclear to respondents, and to verify skip pattern. These items are currently being used in face-to-face and telephone surveys. Initial research in all three communities demonstrates that items are easily understood and that they are generally related to hepatitis B screening as expected.

Discussion

This article describes the process by which an ethnically diverse group of researchers and community members has created, translated, and pilot tested a core set of items to assess hepatitis B testing and related factors, based on a theoretical framework and prior empirical research. The items are comprehensive, and our initial pilot work demonstrates that they are appropriate for liver cancer control research in three Asian American populations. By using similar items in different ethnic groups, we will learn how they are interpreted by members of these groups.

The hepatitis B core set of measures we created has several limitations: Because our Program Project is targeting individual mutable factors of the Health Behavior Framework, our measures are also limited to individual factors such as health beliefs, social support and general or culturally specific barriers. Physician and health care system factors are not directly assessed. Some domains are assessed with single items. However, this compromise may be necessary in some studies to design an assessment tool with reasonable respondent burden while still measuring all constructs that are deemed important.

Conclusions

We constructed three questionnaires in Vietnamese, Hmong, and Korean language (plus English, all versions available upon request) that are slightly different due to cultural and language nuances, but contain a core set of measures assessing identical constructs of the Health Behavior Framework. Utilization of these items in our three intervention trials will provide important information on factors that influence hepatitis B testing and the extent to which these factors can be changed by interventions. We encourage others to similarly utilize theory-based approaches in constructing their measures. Assessment of common theoretical constructs can advance liver cancer control and other health research by facilitating a more systematic comparison of findings across different populations and intervention strategies.

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Table 1

Health Behavior Framework constructs and items associated with hepatitis B testing in bivariate analyses ($p < .05$) in selected study populations

Study Population (Reference)	HBF Construct	Item
Chinese Americans, Seattle, 2005, N=430 (Coronado, Taylor et al., 2007)	Demographics Acculturation Perceived susceptibility Perceived severity MD recommendation Social Support Cultural beliefs	Education \geq 12 years No need for interpreter during doctor visits Chinese are more likely to be infected with hepatitis B than Whites (yes) People with hepatitis B can be infected for life (yes) Hepatitis B can cause liver cancer (yes) Doctor recommended hepatitis B testing Family member suggested hepatitis B testing Friend suggested hepatitis B testing Hepatitis B infection can be prevented by maintaining a positive attitude (yes)
Chinese in New York City, 93% immigrants, 2004, N=429 (Ma et al., 2008)	Demographics Acculturation Access to Care	Married versus other Speaks English very fluently versus fairly/poorly/none Has health insurance
Chinese Canadians, British Columbia, 2005, N=533 (Hislop et al., 2007)	Knowledge of transmission routes Perceived severity MD recommendation Social Support Family history Routine check up	Hepatitis B can be spread during sexual intercourse (yes) Hepatitis B can be spread during childbirth (yes) Hepatitis B can be spread by sharing razors (yes) People with hepatitis B can be infected for life (yes) Hepatitis B can cause cirrhosis (yes) Hepatitis B can cause liver cancer (yes) Doctor recommended hepatitis B testing Family member suggested hepatitis B testing Friend suggested hepatitis B testing Family members are chronically infected with hepatitis B virus Received a complete physical exam during the last year
Korean Americans, 85% immigrants, Los Angeles, 2003, N=140 (Bastani et al., 2007)	Knowledge Perceived susceptibility Perceived severity MD recommendation Barriers	Hepatitis B can be spread via toothbrushes (yes) Hepatitis B spreads more easily than HIV (yes) Hepatitis B patients can appear healthy and be contagious (yes) Hepatitis B is more common among Koreans than Caucasians (yes) Hepatitis B can cause liver cancer (yes) A person can die from hepatitis B (yes) Doctor recommended hepatitis B testing < 3 barriers endorsed
Vietnamese Immigrants, Pennsylvania and New Jersey, N=359, 2004 (Ma et al., 2007)	Perceived severity Perceived susceptibility Barriers Family history MD recommendation	Most people who are infected with HBV will die from liver cancer (agree) I am at high risk for getting hepatitis B infection (agree) Lack of knowledge Do not need test if I feel well Fear of a positive result Language barriers Do not know where to get tests Family member is carrier (yes) Received a physician recommendation to get screened (yes)
Male Vietnamese American immigrants, Seattle, 2002, N=345 (Taylor et al., 2004)	Demographics Access to care Knowledge Perceived severity Family history Cultural beliefs Barriers Communication with provider/provider	Age \geq 50 Has regular source of care (yes) Has regular provider (yes) Hepatitis B can be spread during sexual intercourse (yes) Hepatitis B can be spread during childbirth (yes) Hepatitis B can be spread by someone that looks and feels healthy (yes) Hepatitis B can cause liver cancer (yes)

Study Population (Reference)	HBF Construct	Item
	recommendation	People can die from hepatitis B (yes) Family members are chronically infected with hepatitis B (yes) Illness is a matter of karma or fate (no) Blood tests can deplete the body of energy (no) Had asked doctor for hepatitis B testing (yes) Doctor recommended hepatitis B testing (yes)
Male Vietnamese American immigrants, Seattle, 2002, N=509 (Choe et al 2006)	Demographics Acculturation Access to care Barriers	Age \geq 50, ever been married (versus never married) < 25% of lifetime in the U.S. (versus longer residency in the U.S.) Speaks English not well/not at all (versus fluently or well) Has health insurance Has regular source of care Has regular physician One or more physician visits in the last year (versus none) Having long waits for medical appointment (no) Difficulties getting time off from work (no) Concerns with medical costs (no) Lack of interpreter services (no)

Table 2

Core Items to assess knowledge, beliefs and barriers regarding Hepatitis B, sorted by domains of the Health Behavior Framework

HBF Constructs	Items (response options are yes, no, don't know, refused, unless indicated otherwise)
<p>Knowledge of hepatitis B virus transmission The correct answer, true (T) or false (F), is indicated for each question.</p>	<p>Do you think hepatitis B can be spread from person to person by sharing toothbrushes? (T) Do you think a person can get hepatitis B by sharing food or eating utensils? (F) Do you think hepatitis B can be spread by shaking hands with an infected person? (F) Do you think hepatitis B can be spread from person to person by sharing razors? (T) Do you think a person can get hepatitis B by sharing or reusing a needle, such as acupuncture or injection needles? (T) Do you think hepatitis B can be spread by being next to someone who is coughing or sneezing? (F) Do you think hepatitis B can be spread from person to person during unprotected sexual intercourse? (T) Do you think hepatitis B can be spread from mother to baby during childbirth? (T) Do you think hepatitis B can be spread from person to person by sharing (smoking) a cigarette? (F) Do you think hepatitis B can be spread by eating food prepared by an infected person? (F) If someone is infected with hepatitis B but they look and feel healthy, do you think that person can spread hepatitis B? (T)</p>
<p>Communication with provider/provider recommendation</p>	<p>Have you ever discussed hepatitis B testing with your doctor? Has a doctor ever recommended that you should be tested for hepatitis B? Have you ever asked a doctor to test you for hepatitis B?</p>
<p>Communication with others about hepatitis B</p>	<p>Have you ever discussed hepatitis B testing with people you know such as your family or friends?</p>
<p>Health Beliefs</p>	
<p>Perceived susceptibility</p>	<p>Which of the following groups of people is more likely to be infected with hepatitis B? (Asian group; White Americans; Both equally, don't know, refused) How likely do you think you are to get hepatitis B during your lifetime? Would you say ... Very likely; Somewhat likely; Not likely? How likely do you think you are to get liver cancer during your lifetime? Would you say ... Very likely; Somewhat likely; Not likely?</p>
<p>Perceived severity</p>	<p>Do you think people with hepatitis B can be infected for life? Do you think hepatitis B can cause liver cancer? Do you think someone can die from hepatitis B? Do you think that hepatitis B can be treated? How much would having hepatitis B interfere with your normal daily activities? (A lot, somewhat, not at all)</p>
<p>Efficacy of Hepatitis B testing</p>	<p>Do you think that getting tested for hepatitis B can help you prevent problems with your liver?</p>
<p>Perceived Control</p>	<p>Do you think that getting very sick from hepatitis B is beyond your control? If you were to get hepatitis B, do you think you could take action at your own will to prevent the disease from getting worse?</p>
<p>Social Norms</p>	<p>How many of your friends and family members get tested for hepatitis B? (Most of them, some of them, none of them)</p>
<p>Social Support</p>	<p>Have any of your family members ever suggested that you get tested for hepatitis B? Have any of your friends ever suggested that you get tested for hepatitis B?</p>

HBV Constructs	Items (response options are yes, no, don't know, refused, unless indicated otherwise)
Family history	Does any of your immediate family members such as parents, siblings, children, or spouse/partner have the hepatitis B virus? Are any of these family members living with you in the same household?
Cultural factors/Beliefs	Do you think people avoid those who are infected with hepatitis B? Do you think getting blood tests can deplete the body of energy?
Barriers (Responses are very, somewhat, not at all concerned)	When you think of hepatitis B testing, how concerned are you aboutthe cost of the test? Having to take time off from work?finding out that you are infected?having blood drawn for the test?bringing shame to your family, if the test finds a problem?burdening your family, if the test finds a problem?
Intentions	Are you planning to get a hepatitis B blood test in the next 6 months?

Précis

This paper describes the first steps in the process of constructing a theoretically-based set of measures that is currently used in three trials to reduce liver cancer disparities