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Jevetta Stanford, Alma Biba, Jagdish Khubchandani, Fern Webb, Mobeen H. Rathore

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Community-engaged strategies to promote hepatitis B testing and linkage to care in immigrants of Florida



Jevetta Stanford^a, Alma Biba^a, Jagdish Khubchandani^{b,*}, Fern Webb^a,
Mobeen H. Rathore^a

^a College of Medicine-Jacksonville, University of Florida, Jacksonville, FL 32209, USA

^b Department of Nutrition and Health Science, Ball State University, Muncie, IN 47306, USA

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Abstract To improve early identification and linkage to treatment and preventive services for hepatitis B virus (HBV) in persons born in countries with intermediate or high (>2%) HBV prevalence, the University of Florida Center for HIV/AIDS Research, Education, and Services (UF CARES) employed community-engaged strategies to implement the Hepatitis B Awareness and Service Linkage (HBASL) program. In this brief report, we present a summary of program components, challenges, and successes. Faith and community-based networks were established to improve HBV testing and screening and to increase foreign born nationals (FBNs) access to HBV care. A total of 1516 FBNs were tested and screened for hepatitis B. The majority were females (50.4%), Asians (62.8%), non-Hispanic (87.2%), and they also received post-test counseling (54.8%). Noted program advantages included the development of community networks and outreach to a large population of FBNs. The major challenges were institutional delays, pressures related to meeting program deliverables, and diversity within FBNs populations. Community health workers in the United States can replicate this program in their respective communities and ensure success by maintaining a strong community presence, establishing partnerships and linkage processes, developing a sustainability plan, and ensuring the presence of dedicated program staff.

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* Corresponding author.

E-mail address: jkhubchand@bsu.edu (J. Khubchandani).

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1. Introduction

Hepatitis B virus (HBV) causes a lifelong liver disease chronic hepatitis B (CHB), which leads to cirrhosis of the liver in almost one-quarter of infected individuals and exponentially increases the risk of hepatocellular carcinoma [1]. CHB prevalence is higher in certain parts of the world like Asia and Africa. These trends are reflected in the immigrant populations of the US who identify themselves as Asian or African [2]. According to a recent estimate, a total of 1.32 million foreign born nationals (FBNs) were living in the US with CHB in 2009, where 58% migrated from Asia and 11% migrated from Africa [3]. In another study it was reported that the prevalence of CHB infection among immigrants to North America ranges from 2% to 15%, 40% of whom develop advanced liver disease [4]. The highest HBV prevalence is seen in individuals from Asian and African countries, while individuals from Eastern Europe, the Middle East, and the Pacific Islands also have been identified as having high HBV prevalence. Overall, cases of CHB infection are about 5–10 times more likely to be foreign-born than US-born [1–3].

A need exists to improve early identification of HBV and to enhance linkage to care, treatment, and preventive services for persons born in countries with intermediate or high ($\geq 2\%$) HBV prevalence [5]. In January 2010, the Institute of Medicine released a report which outlined 22 recommendations to improve disease surveillance, knowledge, and awareness of viral hepatitis among the public and providers, access to vaccination, and delivery of viral hepatitis prevention and care services [6]. Despite the Institute of Medicine's recommendations, the number of unidentified HBV carriers in FBN populations remains high [7–11].

A recent review of community-based hepatitis B screening programs in the US by Rein and colleagues [12] found that more than 50 programs were actively working with FBNs. Out of all the programs, 31 initiatives screened more than 20,000 FBNs in the previous year, with an average prevalence of 8.1% for hepatitis B surface antigen (HBsAg). The majority of these programs screened Asian FBNs. These programs, even though very effective, had several limitations. Thus, there is a need for additional clinic and community-based hepatitis B screening programs in the US.

The University of Florida Center for HIV/AIDS Research, Education, and Services (UF CARES) received funding from the Centers for Disease Control and Prevention (CDC) to implement the

Hepatitis B Awareness and Service Linkage (HBASL) Program for FBNs in Jacksonville, FL, USA. Supplemental funding was awarded in September 2013 to expand clinical and outreach efforts. The HBASL program goals were: (1) to increase the proportion of persons who are aware of their HBV status among individuals born in countries with intermediate or high prevalence of HBV infection; and (2) to increase the proportion who receive counseling and are linked to treatment and prevention services [11]. The HBASL program employed community-engaged strategies between January 2013 and September 2014 to test more than 1500 participants from 70 different countries, from both clinic and community settings. The use of community-engaged strategies presented unique advantages and challenges that often required multidisciplinary and unconventional approaches [11].

The purpose of this brief report is to describe the community-engaged implementation strategies of the HBASL program. Also, we present the successes, barriers, challenges, and lessons learned related to the strategies employed during implementation of the HBASL program.

2. Methods

The HBASL program adapted the "Seek, Test, Treat and Retain" model [11–13], shown to be effective in reducing HIV transmission rates in high risk populations similar to our program's target population by: (1) screening, testing, and identifying HBV cases; (2) providing post-test counseling; and (3) linking participants to medical care. Our major goals were: (1) a minimum of 85% of persons who test positive for HBsAg will receive their test results; (2) at least 85% of persons tested for hepatitis B will have their risk factors documented, including country of birth; (3) at least 90% of cases identified during the project period reported to the appropriate state/local health department within 6 months of diagnosis date; (4) a minimum of 75% of persons who test positive for hepatitis B will receive post-test counseling; and (5) a minimum of 75% of persons who test positive for hepatitis B are referred to care, treatment, and preventive services.

The HBASL program differs from similar HBV outreach programs like the San Francisco Hepatitis B Free Campaign, by targeting a broad audience of FBNs [persons born in countries with intermediate or high ($\geq 2\%$) HBV prevalence] rather than those born in a specific country [10]. All program activities occurred in an urban locale in both clinical

and community settings. Clinical settings included an emergency department at the local safety-net hospital and two community health clinics, all of which serve patients with a challenging payer mix and experience moderate to high patient volume. Community settings included a variety of community and faith-based organizations and settings frequented by FBNs (i.e., local refugee servicing organizations and culturally focused community events organized by FBNs). The HBASL program set up on-site outreach clinics at community settings during events to facilitate testing activities.

Screening, testing, and case identification activities included providing FBNs with an HBV risk assessment and no cost HBV test. Paid staff of the HBASL program, culturally competent community health workers (CHWs), and certified medical assistants (CMAs) led the screening and case identification efforts, under the supervision of the HBASL program manager. FBNs were offered the opportunity to participate in the HBASL program by CHW/CMAs in the clinical or community setting. Communication barriers were reduced by translating program materials (i.e., written screening consent, educational materials, and test result notification letters) into 13 different languages (Bosnian, Croatian, Hindi, Kirundi, Vietnamese, Spanish, Arabic, Cambodian-Khmer, Russian, Swahili, Chin, Nepali, and Burmese) [10–15]. All participants completed a written consent prior to testing. CHWs summarized the contents of the consent and allowed time for each participant to read and ask questions before signing. After signing the consent, CHWs/CMAs assisted FBNs to complete the HBV risk assessment. The HBV risk assessment, developed by the CDC specifically for grant recipients, captured demographic (i.e., country of birth, gender, race, ethnicity, and health insurance) and risk factor data of participants. Next, CMAs collected a blood sample for the HBsAg and the total hepatitis B core antibody (anti-HBc) serologic test analyses. Participants received culturally appropriate education and awareness materials and instructions on receiving post-test counseling and results, and a \$15 gift card participation incentive. Initially, the participation incentive was a \$10 gift card provided after testing and then \$5 provided at test results picking up and post-test counseling to encourage participant follow up. The incentive compensation was later changed to provide the entire participation incentive after completing the HBV testing, as the compensation split did not improve participant follow up. This

helped participant motivation to complete the program and improved program sustainability.

At the time of the HBV test, participants received instructions on ways to get their HBV test results and post-test counseling, which included participating in an outreach post-test counseling event, visiting the main program clinic, or scheduling a community or home visit with a CHW, which was especially useful for those without transportation. Outreach post-test counseling events were conducted in conveniently located community settings, typically the community setting in which the initial outreach HBV testing event occurred. Participants were notified of outreach post-test counseling events by mail and by posted flyers within the community setting in which the testing event occurred (i.e., at apartment complexes, grocery stores, places of worship, etc.). All blood samples for this project were analyzed by the Florida Department of Health state laboratory at a reduced rate. The state laboratory required that specific demographic information (i.e., name, address, and telephone number) was included with each sample to ensure accurate processing. Positive cases were reported to the state health authority by the state laboratory staff after analyses were complete. Participants received their HBV test results and risk reduction education during post-test counseling. Risk reduction education was conducted in participants' language through standardized material in different languages or through translators or family members who understood English. Risk reduction education involved details about HBV transmission, infection, health effects, prevention, and treatment.

HBV serologic test results interpretation by risk level and number of HBASL participants are outlined in [Table 1](#). Low risk test results were mailed via US certified mail with risk reduction educational materials post-test. More intensive contact attempts were made for participants with high risk test results, participants with HBsAg positive results. Participants with high risk test results were contacted by phone in order to schedule an in-person appointment to provide test results and conduct post-test counseling; test results were never provided over the phone. During the in-person sessions, CHWs conducted an HBV risk reduction education with the participant and provided education materials. Afterward, CHWs confidentially provided each participant with their test result explanation letter and explained what their test result meant. HBsAg positive participants were linked to care and vaccination services accordingly.

Table 1 Hepatitis B virus (HBV) serologic test results.

HBV serologic test result interpretation	HBV serologic test results	Risk level	HBASL program participants <i>n</i> (%)
Negative	HBsAg (–) Anti-HBc (–)	Low	1020 (67.2)
Negative susceptible	HBsAg (–) Anti-HBc (+)	Low	417 (27.5)
Indeterminate	HBsAg (unknown) Anti-HBc (unknown)	Low	11 (0.7)
Positive	HBsAg (+) Anti-HBc (+)	High	68 (4.4)

Anti-HBc = hepatitis B core antibody; HBASL = Hepatitis B Awareness and Service Linkage; HBsAg = hepatitis B surface antigen; HBV = hepatitis B virus.

Certified letters were mailed to nonresponsive HBV positive participants as the second contact attempt. Positive HBsAg test results were never provided by mail. Home visits to the last known address were made as the third and final attempt. Nonresponsive participants with positive HBsAg test results that were not reached after three unsuccessful attempts were documented as lost to follow up.

HBASL participants were linked to services based upon their test results: (1) participants with an indeterminate test result were offered another free HBV test; (2) HBsAg negative and/or negative susceptible participants were linked to free vaccination services at the local health department; and (3) participants with HBsAg positive test results were linked to medical care. Service linkage information was included on the test result explanation letter received during post-test counseling.

HBsAg positive participants with health insurance were linked to the UF Health Division of Gastroenterology for further evaluation. HBsAg positive participants without health insurance were linked with UF Health financial services to determine eligibility for indigent care. HBsAg positive participants were also linked with free and/or low cost medical resources for immediate evaluation while waiting on eligibility determination. CHWs documented initial appointment dates.

A major component of our program methods was use of information technology. UF CARES had the capacity to successfully enter and retrieve clinical information using the Research Electronic Data Capture (REDCap) data collection systems, which served as the data collection system for this project. The REDCap data collection system meets the requirements established by United States Department of Health and Human Services (USDHHS). REDCap is a secure, web-based application designed to support traditional case

report form data capture for projects. REDCap streamlined the data collection process for rapidly developing databases. The development of project specific data management systems was simplified as users could create a project, define and organize the data to be captured, build related forms, and associate them with project events.

3. Outcomes

3.1. Services provided

From January 2013 to September 2014, the HBASL program employed community-engaged strategies to improve HBV testing and service linkage for FBNs and provided the following services: 1516 individuals underwent HBV test and screening, 831 individuals received post-test counseling and, 43 HBsAg positive participants were linked to medical care. The majority of participants were female (50.4%), Asian (62.8%), non-Hispanic (87.2%) (Table 2).

3.2. Program successes

The HBASL program's greatest success was the development of a network of faith and community-based organizations. During the program period, the HBASL program established both formal and informal partnerships with 38 faith and community-based organizations to improve HBV testing and care for FBNs. Informal partnerships with community organizations were formed by HBASL program staff to conduct outreach HBV testing and test result distribution to participants. Oftentimes, the staff at community organizations would offer information about other community organizations and upcoming community events to conduct outreach testing. These informal partnerships drove outreach activities for most of the project period, and included refugee servicing

Table 2 Hepatitis B Awareness and Service Linkage (HBASL) program outcome and participant demographics.

Program outcomes	n (%)
HBV testing, awareness, & care linkage	
Tested	1516 (100)
Post-test counseling	831 (54.8)
Linked to medical care	43 (2.8)
Participant demographics	
Gender	
Male	734 (48.4)
Female	764 (50.4)
Race	
Asian	953 (62.8)
White	290 (19.1)
Black	178 (11.7)
Other	95 (6.2)
Ethnicity	
Non-Hispanic	1323 (87.2)
Hispanic	57 (3.7)
Continent of birth	
Asia	1182 (77.9)
Africa	171 (11.2)
South America	122 (8.04)
Europe	37
Australia/Oceania	4
Insurance status	
Insured	
Public	430
Private	313
Uninsured	600

HBV = hepatitis B virus.

organizations, churches, mosques, worship temples, community events and celebrations, grocery stores, and apartment complexes. In an effort to maintain, manage, and monitor the informal partnerships, the HBASL program held monthly meetings to promote open communication among partnering organizations. As the diversity of the participating partnering organizations increased, partners began to see themselves as members of an informal network devoted to HBV testing and care. The monthly network meetings served as a forum to discuss coordination and referral system challenges, collaboratively develop solutions to identified challenges, and identify additional opportunities for testing and treatment opportunities. Additionally, a formal partnership via a memorandum of understanding with the local refugee health clinic was established that increased screening and case identification activities beyond the stated project period.

We partnered with more than three dozen community organizations for services provided. The majority of the community based hepatitis B screening programs in the US do not provide HBV

treatment services [10–13]. All of our partner organizations had prior experience with viral hepatitis testing, prevention, and treatment, and either directly or indirectly provide HBV testing and linkage to care among FBNs. No one organization offered comprehensive services for HBV prevention and treatment; the organizations function collaboratively to provide comprehensive HBV prevention and treatment services to FBNs. Our program acquired the innovative collaborative approach, and partner organizations referred FBNs for screenings and linkages to services and provided outreach venues for FBNs to receive testing, prevention and vaccination services, and/or treatment services [12,13].

Data management was a large component of our program's ability to successfully monitor and track client data in order to measure performance opportunities, performance successes, and adhere to the reporting requirements of data collection system requirements established by USDHHS. Medical assistants were responsible for entering client level data into the REDCap system on a real-time basis. The administrative program manager provided monitoring and oversight of the data management process and workflow. As participants were tested in the field, medical assistants completed a risk assessment form as per USDHHS, and entered pertinent medical information into the REDCap data collection system. On a monthly basis, the data coordinator ran a report for each participant entered into the REDCap system to ensure data quality, completeness, and integrity. This provided an efficient system to capture data needed for quarterly and *ad hoc* reporting.

The majority of the programs in the US exist in the mid-Atlantic or the Midwestern region [10–12]. Our program is the first in Southeastern US. In addition, the majority of the programs in the US serve and focus on Asian populations. Our program had a very high proportion of individuals of African descent. Our program reached out to more than 1500 FBNs which is higher than the national average (21,817 individuals covered by 31 programs across the US in the past year) [12]. Finally, our clients were more diverse than the programs nationwide in relation to language, age, gender, insurance status, and other demographic factors. This was in part due to community-engaged strategies used for diversification of program participants [12–14].

3.3. Program barriers and challenges

The greatest barrier of the HBASL program was institutional processes required on behalf of the

HBASL program's parent organization and the funder. Initiation of testing activities was delayed, at the request of the funder, in an effort to finalize evaluation metrics for all grant awardees, which created a subsequent delay in internal institutional review board approval. Another noted barrier was the unintended event cancellations. The target audience was diverse and required carefully designed, culturally competent services (e.g., translation of program materials into 13 different languages), which was cumbersome and led to occasional delays and participant recruitment problems [12–15].

Hu and colleagues [15] suggest that multiple barriers exist for FBNs to accessing HBV treatment services, which include but are not limited to individual, provider, and health care system related barriers [15]. We addressed all of these barriers. For example, individuals were educated about HBV, its transmission, and health-related consequences, and language and cultural beliefs or social stigma that could be barriers to screening and treatment were addressed [14,15]. FBNs are concerned about the cost of treatment, misconception that nothing can be done, and the concern about the impact on life and health insurance, which we could address with great success. Provider barriers include gaps in health care provider knowledge about HBV, lack of knowledge of risk factors, underestimation of the risk among FBNs, and differences in cultural background of providers and FBNs [15]. Community-engaged strategies were utilized to recruit diverse groups of FBNs and constant training and education were provided to program staff and health care providers about the FBN population, their beliefs, and cultural characteristics that could play a role on HBV screening and treatment [11–15]. Cultural competence was at the core of our program services and staff training. Health care system barriers for FBNs include the lack of understanding of the US health insurance system, lack of health insurance, and underutilization of health insurance for those with coverage. Our target audience had a large proportion of FBNs without insurance and appropriate services for indigent care had to be mobilized. This was accomplished through welfare agencies, charitable health care services, and helping FBNs enroll in state sponsored health insurance for the poor (i.e., Medicaid enrollment). Despite our multi-pronged approach and efforts to improve outreach, there were clients who could be missed due to a number of reasons unique to such screening programs (i.e., individual, provider, and system level barriers).

Constant program evaluation (i.e., process and formal) helped identify challenges. For example, the incentive pattern had to be changed. Repeated follow-up contacts had to be incorporated. Participants with major language, social, and cultural barriers had to be reached through multiple avenues. Also, those who had no insurance (a major group) had to be referred to various agencies, were helped with paperwork, and eventually linked to some health services as soon as possible. Despite all these efforts, we found a lower number of hepatitis B cases in our population compared with the average across all programs in the US (4.4% vs. 8.1%), which could be due to missing true positive cases.

4. Implications for practice

Employing community-engaged strategies to improve HBV testing and service linkage in FBN populations should be considered when planning programs. Nationwide, CHWs can replicate this program and play a critical role in screening FBNs for HBV. Also, practitioners can implement programs that are community focused, tailored to individual needs, culturally sensitive, and evidence-based to improve preventive behaviors and treatment of HBV infections in FBNs. A few vital lessons learnt are as follows.

4.1. Maintain a strong community presence

Community partnerships were a direct result of the strong community presence the HBASL program maintained throughout its existence. The HBASL program maintained a strong community presence by: (1) establishing relationships with leaders of ethnic faith and community-based organizations; (2) actively participating in social and health care networks targeting FBN populations; and (3) conducting outreach activities and events for FBN populations. By employing these strategies, the HBASL program established itself as a community partner offering a valuable service.

4.2. Establish partnerships and linkage process

The HBASL program benefited tremendously from the partnerships formed with faith and community-based organizations. Oftentimes, partners are able to provide needed services beyond the scope of the program. Furthermore, forming partnerships, both informal and formal, should be done during the program planning phase, if possible. Specific to formal relationships development,

early relationship initiation can help to alleviate delays that can impact program outcomes and deliverables. Local health care facilities can help provide access to care if appropriately incentivized and linked with the outreach program.

4.3. Develop a sustainability plan

The HBASL program provided a valuable service to the FBN population in northeast Florida. Processes were established to ensure that this population continued to access these services. Working closely with community partners to establish these processes should be done during the program planning phase, if possible. Challenges in early diagnosis and referral system for HBV can be reduced if local health care providers participate actively in the HBASL program. Community-based organizations along with local health care providers/primary care physicians will help increase the success rate of such programs. Primary care physicians could be given participation incentive/incentive for participation in such programs.

4.4. Ensure the presence of dedicated program staff

Making provisions for dedicated program staff to implement time intensive program activities is key to program success, specifically as it relates to community presence, partnership development, and service linkage. Often, the significance of these program activities is marginalized. As a cost saving technique, program directors often allot partial staff and resources to execute these roles in programs. Program staff, with a minimum of 0.75 full time effort should include: (1) a program manager; (2) outreach coordinator; (3) clinical coordinator; (4) medical assistants; (5) medical case manager; and (6) data manager with clearly defined roles and expectations of/for each.

5. Conclusion

The HBASL was an outreach program funded by the CDC to initiate screening and linkage to care for HBV infection in immigrants of Northeast Florida. Overall, the program was able to reach out to a large population of FBNs through community partnerships and linkage services. Program participants received screening and counseling for HBV. The program can be replicated across the nation to reach out to the high risk population of FBNs. With appropriate components and planning, program success can be assured.

Conflicts of interest

The authors declare no conflicts of interest.

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