THE TIME IS NOW
END THE EPIDEMICS

LINKAGE TO CARE OF MOTHERS AND CONTACTS IDENTIFIED THROUGH THE PERINATAL HEPATITIS B PREVENTION PROGRAM

TARGET POPULATION	Women with hepatitis B infection in the immediate post-partum period, and their contacts
LOCATION	New York City (NYC)
PROGRAM DESIGN	Telephone navigation intervention to improve maternal engagement in care after childbirth. Initially a research project and currently an ongoing program.
ESTIMATED COST	$180,000 per year for 2 years (does not include in-kind support)
FUNDING SOURCE	Gilead Sciences, Inc.

SUMMARY

The New York City Department of Health and Mental Hygiene developed and implemented a pilot project to provide telephone outreach and navigation services to women identified with hepatitis B during pregnancy. The program was adapted from a National Cancer Institute Research-Tested Intervention (for more information click here, available at: The goal of the project was to provide health education and patient navigation services to increase maternal engagement in hepatitis B care after delivery to prevent the development of liver cancer and liver disease. Viral hepatitis is the leading cause of hepatocellular carcinoma, the most common form of liver cancer, worldwide, and in the United States (U.S.). Further, in the U.S., Asian Americans and Pacific Islanders have the highest hepatitis B-related mortality rate and are disproportionally affected by liver cancer.

BACKGROUND

There are approximately 1.25 million people living with hepatitis B in the U.S. ; 230,000 people are estimated to be living with hepatitis B in NYC. The burden of hepatitis B in the U.S. is greater among people born in regions of the world with high or moderate prevalence of chronic hepatitis B, including much of Asia, Africa, Eastern Europe, and the Pacific Islands. A number of barriers exist that prevent people living with hepatitis B from accessing care including: language barriers, low health – and health systems, literacy, limited hepatitis B education, a fragmented and complicated health delivery system, and lack of access to health insurance. The New York City Department of Health and Mental Hygiene developed a navigation program to help women overcome these barriers. This pilot project used surveillance data to identify women with hepatitis B in the immediate postpartum period to prioritize for outreach. This navigation pilot successfully enrolled 409 women, 73% of whom attended a hepatitis B medical appointment within six months of delivery.

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CORE ACTIVITIES

The New York City Department of Health and Mental Hygiene developed a culturally and linguistically competent navigation program to help women living with hepatitis B navigate medical care after childbirth. Pregnancy is an important time to engage women living with hepatitis B in care, as during this time they are routinely screened for hepatitis B infection, are likely seeing a prenatal care provider, and have near-universal access to health insurance during pregnancy. In addition, CDC funds perinatal hepatitis B prevention programs nationwide to provide case management to pregnant women to help prevent mother-to-child transmission. The CDC program presents a potentially unique opportunity to proactively offer linkage to care for pregnant women using the approach developed by the New York City Department of Health and Mental Hygiene. NYC's navigation approach includes:

- Identifying and reaching eligible mothers by telephone;
- Establishing relationships with local hospitals, health clinics, and community-based organizations to create a strong referral network and capacity for navigators to provide warm hand-offs when intensive in-person services were required;
- Establishing rapport with participants, providing standard health education, using a structured, interactive assessment to identify barriers and facilitators to engagement in care, participating in problem solving with participants, and linking patients to supportive resources and assistance;
- Creating a service plan, tracking appointments, making referrals to and coordinating with hospitals, health centers, and community-based organizations;
- Providing navigation services for up to six to 12 months when needed to ensure continued engagement in care.

The New York City Department of Health and Mental Hygiene hired staff representative of communities most affected by hepatitis B in NYC to ensure that participants received culturally and linguistically competent care; navigators spoke English, Mandarin, Cantonese, Wolof, and French. For other languages, navigators used LanguageLine® to provide interpretation services. A system was developed to assign patients for outreach on a weekly basis. At least one attempt was made to call each woman. If the navigator was able to make contact, they confirmed the person's identity and asked for verbal informed consent to participate in the project; study protocol and forms were all reviewed and approved by the New York City Department of Health and Mental Hygiene IRB. Brief, structured hepatitis B education was provided to all participants, and they were assessed by navigators using a semi-structured phone interview. This provided an opportunity to build rapport, and to create a basic navigation service plan. The navigator offered support in scheduling an appointment such as making a three-way call with the provider and patient if needed.

The patient navigator followed up the day before the appointment to see if there were any potential barriers that would prevent the patient from attending their appointment. If determined to be necessary during the assessment, the navigator would ask the patient to call during the appointment to support the patient in their discussion with the provider. If needed, they helped navigate the client through patient assistance programs to access medication, or to identify a new provider. They also supported women to access other services such as family planning, mental health, and primary care. Services were offered to all adult contacts of women in the program, although only about 5% of women referred any contacts for testing, immunization, and/or navigation services.

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DATA

409 women participated in the pilot project. Of these, 36% had less than a high school education, 99% were born outside the US, 73% identified as Asian and 8% identified as Black/African American. Sixty-seven percent were born in East Asia (vast majority from China) and 19% were born in Sub-Saharan Africa. Sixty-three percent could not communicate in English, and 29% were uninsured or only had temporary insurance during pregnancy. The majority (73%) attended an appointment with a hepatitis B medical provider within six months of delivery.

EVALUATION

NYC is currently evaluating the results of the pilot project and will continue the program as a non-research program. The evaluation will focus on outcomes and will use electronic laboratory reports from the surveillance system to assess whether a participant had a medical visit with a hepatitis B medical provider within six months of delivery. Results are anticipated to be published in 2020.

FUNDING & COST

The cost of the program was $180,000 per year which primarily supported staff and overhead such as cell phones, desks, computers, etc. In-kind support in the form of project management and surveillance were provided by the New York City Department of Health and Mental Hygiene.

STRENGTHS

- Having staff in place to do the navigation work was the most critical aspect of the program;
- A multi-disciplinary team including health departments, hospitals, health centers, and community-based organizations brings a variety of helpful perspectives that allow the program to support the whole needs of the person;
- Staff that represent the community being served and can provide in-language support are critical to navigating barriers in a culturally and linguistically competent manner;
- Strong hepatitis surveillance and prevention programs provided the foundation and framework to conduct this pilot project;
- Flexibility within the program to adapt to the circumstances and evolving needs of the pilot project participants;
- This approach used a person-first framework which allowed participants in the pilot to not only access medical care for hepatitis B, but also helped identify and support other unmet needs or health conditions such as childcare, birth control and diabetes.

LIMITATIONS

- Services are not always available in the language needed and although the navigation staff spoke a range of languages, not all needs could be addressed/included directly through the navigators;
- Lack of awareness and knowledge of hepatitis B among patients and providers;
- Although safety-net hospitals and federally qualified health centers offer sliding-fee scales and low-cost services, pricing systems often lack transparency and do not allow patients to know that a sliding scale exists, that they can apply for it, or ensure the patient understands the costs upfront;
- Extensive paperwork and documentation are required to access the healthcare system that marginalized populations often do not have access to;
- Belief that one cannot access public benefits depending on one's immigration or application status;
- There are not standardized best practices and approaches to developing a telephone hepatitis navigation program, thus "trial and error" was necessary to determine an appropriate case load;

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- Existing staff could not address the full workload of patients in need of support; more staff are needed to address the full community in need;
- There was not much uptake on the offer to provide navigation support to family and household contacts of women enrolled in the program, and this part of the program was not as well received as initially thought.

STAKEHOLDERS

The New York City Department of Health and Mental Hygiene Viral Hepatitis and Perinatal Hepatitis B Prevention Programs, community-based Check Hep B Patient Navigation Programs, including: African Services Committee, Apicha Community Health Center, BronxCare Health System, Charles B. Wang Community Health Centers, Korean Community Services, Montefiore Medical Center, NYU Langone Family Health Centers, and the NYC Health + Hospitals system.

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