

Adapting the Andersen Model to a Francophone West African Immigrant Population: Hepatitis B Screening and Linkage to Care in New York City

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Abstract Hepatitis B virus (HBV) is highly endemic in West Africa and immigration from this region to the United States has greatly increased over the past quarter century. Using the Andersen Model as a conceptual framework, this study qualitatively examines francophone West African immigrants' perceptions of factors affecting access to HBV screening and linkage-to-care in New York City. Four focus groups were conducted with 39 purposefully selected participants. The focus groups were conducted in French, audio-recorded, translated into English, transcribed, analyzed, and coded for major themes. Participants identified increasing knowledge of HBV and opportunities to access care in a culturally-sensitive manner that decreases fatalism and avoids generating stigma as priorities. They also emphasized the importance of engaging religious establishments and social networks and employing the Internet to disseminate HBV-relevant information. Cost and health insurance are identified as future challenges that will need to be addressed in a health care environment in which undocumented immigrants are ineligible for health insurance. The qualitative analysis in this study highlights the recursive and interdependent nature of the Andersen

Model, and a modification of the model is proposed that is intended to inform examinations of other minority communities' access to health care.

Keywords Hepatitis B · Immigration · West Africa · Qualitative research

Background

Approximately two billion persons have been infected with the HBV, 360 million of whom are chronically infected, and 600,000 of whom die annually from HBV-associated deaths [43, 44]. Although a global epidemic, HBV disproportionately affects sub-Saharan Africa where the prevalence is >5 % [35]. Within sub-Saharan Africa, West Africa appears to have the highest rates of chronic infection with a prevalence of >8 % [35] with those who have not benefited from recent widespread childhood HBV vaccination campaigns most at risk [19].

Over the past three decades, emigration from Africa to the United States (US) has grown significantly with a

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seven-fold increase in the number of African-born US residents between 1980 and 2009 (an increase from 200,000 to 1.5 million persons) [30, 32]. This expanding population disproportionately contributes to the burden of HBV in the US, as African immigrants make up <0.5 % of the total US population but 11 % (150,000 persons) of the 2.2 million persons infected [27]. The plurality of sub-Saharan African immigrants in the US originate from West Africa, and the HBV prevalence among this group to be as high as 13 % [27]. This disproportionate burden of HBV also appears to be present among West African immigrants in NYC, among whom a recent screening program found a 11.4 % positivity rate [8].

In response to this situation, the US Department of Health and Human Services has initiated a concerted effort to improve HBV services, which includes a Centers for Disease Control and Prevention-led initiative to systematically gather HBV-related health information on racial and ethnic minorities [23, 22]. Although this federal support is essential, the marked demographic and cultural diversity of those at risk highlights the need to develop population-specific HBV screening and linkage-to-care strategies [42].

Theoretical Framework

To further this goal and better understand HBV-related health service utilization among African immigrants in NYC, this study proposes an adaptation of the Andersen Model for Vulnerable Populations.^{10,11} The Andersen Model was originally created in the 1960's to explain and predict why families and individuals use health services, to inform policy, and to increase access to health care equitably. The model's original formulation proposed that health service utilization is a function of predisposing factors, enabling or impeding factors, and need for care. Predisposing factors include demographics, health beliefs, and social structure; enabling factors include personal, family, and community resources; and need is both perceived (by the individual), and evaluated (by a health professional). Subsequent iterations of the model incorporated the health care system, consumer satisfaction, health status outcomes, and highlighted the recursive and interconnected nature of the model's different categories [3, 4, 5, 6]. This paper qualitatively explores a theoretical adaptation of the Andersen Model to the needs of West African immigrants in HBV with regards to HBV screening and linkage-to-care.

Rationale and Aims

The disproportionate burden of HBV infection in African immigrants in the US and the limited knowledge and access to care among those who are infected call for a deeper

understanding of factors affecting access to HBV vaccination, screening, monitoring, and treatment in this population. Most research on knowledge and attitudes towards HBV among immigrant communities in the US has been limited to Asian communities, despite the equally high rate of HBV among African immigrants [36]. Additionally, this study proposes a theoretical adaptation of the Andersen Model that may be relevant for other communities.

Methods

We used qualitative methods that consisted of convening an advisory committee, developing focus group moderator guides, recruiting participants, conducting the focus groups, analyzing their transcriptions, and developing overarching themes within the framework of the Andersen Model.

Advisory Committee

We convened an advisory group of African community organization leaders, community health workers, and experts in the field of viral hepatitis. This group lent their expertise regarding African immigrants' understanding of and attitudes towards HBV screening, as well as how HBV is currently screened for and managed in NYC's health care system.

Ethical Approval

Approval by the Icahn School of Medicine at Mount Sinai Institutional Review Board (HS#: 11-02192, GCO#: 12-0033(0001)(01) ME) was obtained prior to initiating the study.

Participant Recruitment

Recruitment was targeted towards both community leaders as well as lay persons in the community. Target participants specifically included religious leaders, mutual aid organization representatives, former or current health workers, and both immigrants who have arrived recently and more distantly. This a priori purposeful approach was selected in order to include participants with broad perspective on the communities they represent, as well as members in the community without leadership roles who might provide a more individualized perspective.

Two community health workers recruited participants after a training that included how to introduce the study in a manner that avoided coercion and ensured confidentiality when approaching potential participants. The community health workers are themselves West African immigrants,

speak several West African languages, and have worked in the New York African immigrant community for many years. The community health workers recruited participants from local mosques, community centers, hair-braiding salons, and taxi garages in Harlem, NYC, by distributing flyers in English and French and through face-to-face conversations at these locations. Inclusion criteria included being born in sub-Saharan Africa and being over 18 years of age. The target number of participants was 8–10 per focus group. Sample size was determined based on a goal of a minimum of two focus groups with additional focus groups to be conducted until saturation was achieved.

A moderator guide for the focus groups was developed based on Andersen Model themes including predisposing, enabling/impeding, and need factors. The principal investigator translated the moderator guides into French, back translated the guides into English to check accuracy, and piloted the guides with four members of the advisory committee.

Focus Groups

After obtaining informed written consent, four focus groups were held at the partnering community-based organization in Harlem. Participants were provided a meal, a round-trip Metrocard, and a twenty-dollar gift card. Members of the research team who are bilingual and trained in qualitative research methods moderated the focus groups, which were held in French or English. The focus groups included mixed groups of men and women above 18 years of age. All focus groups were audio-recorded, professionally transcribed verbatim, and then translated into English, as needed.

The principal investigator acted as the primary moderator, while one or two other members of the research team maintained written notes and oversaw the focus group audio recordings.

Coding and Analysis

Code Development

The moderator deductively created an a priori list of preliminary codes based on predisposing, enabling, and need factors in the Andersen Model [5, 16]. Two members of the research team then built on these preliminary codes through an inductive process as the analysis of the transcription was carried out in order to identify necessary additions, deletions, or modifications. Development of the code structure was carried out until no new codes emerged and saturation was achieved [18].

Table 1 Focus group demographic characteristics (n = 39)

Variable		Median/ count	SD/ percent
Age		39	15
Female		12	31 %
Has no PCP		25	66 %
Uninsured		29	78 %
Ever tested for HBV		21	54 %
Country of birth ^a	Burkina Faso	10	26 %
	Guinea	5	13 %
	Mali	4	11 %
	Senegal	12	32 %
1st language ^a	French	9	24 %
	Moré	8	21 %
	Wolof	10	26 %
English reading/writing level	Basic	19	50 %
	Intermediate	12	32 %
	Fluent	7	18 %
Highest grade completed	0–8	12	31 %
	9–12	6	15 %
	>12	21	54 %
Employment status	Employed	7	18 %
	Unemployed	27	69 %
	Student	5	13 %
Years lived in US	≤3 years	18	49 %
	4–10 years	9	21 %
	>10 years	10	27 %

^a Only shows countries/languages contributing >10 % of total

Transcript Analysis

Two members of the research team read through the entire transcripts soon after the focus groups to gain an overall understanding and familiarity of their content. They then independently and manually coded the first focus group transcript and established an inter-rater reliability of >80 %. A primary coder subsequently coded the remainder of the transcripts according to the method outlined by Bradley et al. [9].

Adaptation of the Theoretical Model

In carrying out the analysis, we used the codes to assess and adapt the overall structure of the Andersen Model, the themes it outlines, and the overall theory it proposes in order to generate an adaptation of the model that is specific to francophone West African immigrants in NYC. In developing this adapted model, we also incorporated elements and themes that emerged from input from the

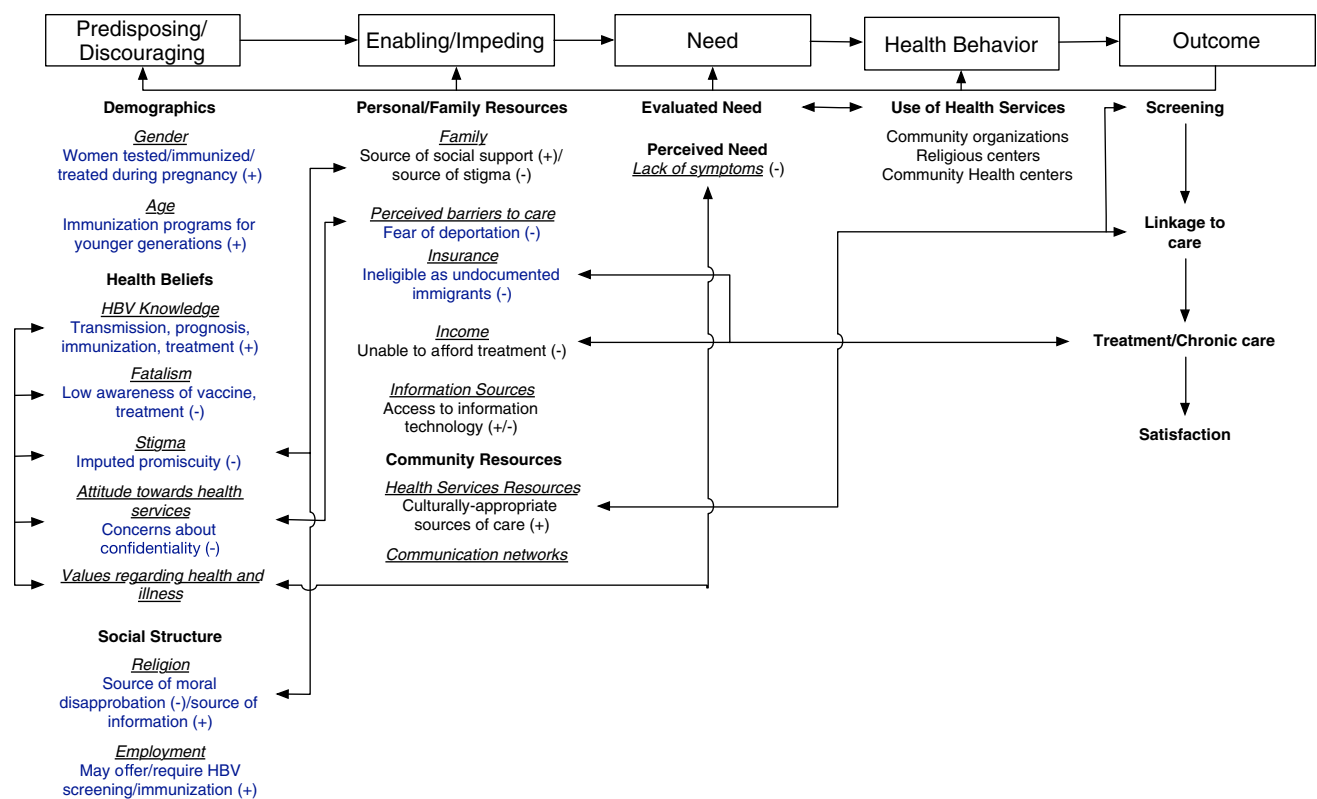


Fig. 1 Blue modifications of the Andersen Model identified in this study as specific to the West African francophone population in NYC (Color figure online)

advisory committee and became apparent through the literature review.

Results

Demographic Characteristics

We conducted four focus groups lasting an average of 79 min each with 39 participants of whom the majority (69 %) were men (Table 1). All groups were conducted in a combination of English and French as required by individual participants. The median age was 39, two thirds (66 %) of participants had no primary care physician, and over three quarters (78 %) were uninsured. Over half (54 %) reported having received an HBV test in the past. All participants were from West African countries, the majority of which (87 %) were francophone, and half (50 %) reported limited English reading and writing skills. While the majority reported having a greater than high school level education (54 %), less than one fifth were employed (18 %). Almost half (49 %) had arrived in the US within the past 3 years.

We identified themes consistent with those already described in the Andersen Model, as well as new themes and relationships between themes as described below (Fig. 1).

Predisposing/Discouraging

Four themes emerged within the predisposing/discouraging domain: demographic factors, health beliefs, and social structure.

Demographics Factors

Although demographic factors were not discussed during the focus groups, the advisory group highlighted the important role they have in predisposing members of the West African immigrant community to getting care. Demographic factors are particularly important regarding gender and age as all pregnant women who receive routine prenatal care in the US are screened for hepatitis B surface antigen, and HBV vaccination is now part of routine childhood vaccination programs in the US as well as most West African countries.

Health Beliefs

Under health beliefs, four sub-themes emerged: knowledge of HBV, fatalism, stigma, attitudes towards health services, and values regarding health and illness, which in contrast to the demographics theme, all emerged from the focus group transcript.

Regarding HBV knowledge, there was a general consensus in the focus groups that there is limited knowledge of HBV within African immigrant communities, including its route of transmission, course, and prognosis. Participants stated that incomplete knowledge could contribute to an attitude of fatalism that discourages individuals from accessing care. As one 43-year-old Senegalese man explained, members of his community would be more likely to seek care if they knew that a vaccine and treatment are available:

“Because when you explain to someone that there is a very serious disease, you must at the same time let them know that there is a way to prevent it. Only then will they take doing something about it seriously.”

In contrast to the participants’ perceptions of increasing awareness of prevention and treatment, the discussion around knowledge of transmission was more divided. Some participants described awareness of sexual transmission of HBV without knowledge of vertical and early childhood horizontal transmission could contribute to stigma and discourage seeking care. As one 42 year-old Burkinabé taxi driver stated:

“You have to consider that the fact that it can be sexually transmitted could create a certain degree of shame, and that people would hide their status to avoid being judged.”

In addition to stigma, certain participants stated that members of their community could also be concerned regarding the confidential nature of health services. This concern related both to the fear that other members of their community may find out their status, and that their identity may be revealed to immigration enforcement. In relation to this later point, one 27 year-old Cameroonian man stated,

It is most important to make them [African immigrants] understand that everything will be confidential. Because most African immigrants are here illegally - so I think that every time they tell us that you can get treatment, there is the fear that they will search our files. And that is why most Africans do not want to go to the hospital.

Values Regarding Health and Illness

Focus group participants also described their interconnected and interdependent relationships particularly as they relate to values surrounding health and illness. In discussing how health beliefs impact access to care, several participants described a relationship between knowledge, fatalism, fear of disclosure, stigma, and African cultural beliefs. For example, a 38 year-old woman from Burkina

Faso described how stigma and fear of disclosure more accurately reflects a lack of knowledge rather than African cultural norms:

I think that we often speak about cultures of confidentiality in the African community, but we have to face the fundamental problem: it is not just this story of customs and cultures, but really it is ignorance. It is fundamentally the lack of knowledge that is tied to lack of access to treatment and other public health methods.

Other participants commented on similar relationships between knowledge and stigma. The same Burkinabé taxi-driver quoted above stated,

One of the fundamental problems is the lack of awareness and access to information. But at the same time, we talk a lot about stigma and shame and the reputation of the family when you say someone is sick... If people have more awareness this [stigma] shouldn’t be a problem... The important element is to know that if you have this illness, you can be treated, and that if you don’t have it, you can get vaccinated.

Social Structure

Within the social structure theme, participants, who were exclusively Muslim, discussed the roles that religion plays in West African’s experience of health and illness. Participants discussed how information about HBV screening and linkage to care opportunities can be disseminated by imams at Mosques, thereby further predisposing members of the West African community to connect to care. As one 27 year-old man from Guinea stated, “Imams can help us better educate communities. Friday prayers are a very good way to convey the message.”

In contrast, participants also discussed the potential role of religion as a deterrent to seeking care as moral codes imparted through religion could potentially serve to increase stigma against people with HBV.

Participants also discussed how employment in health care fields where HBV screening and vaccination are required could predispose people to be connected to care. As one 48-year-old Guinean woman stated, “I was vaccinated because of my job, an introduction of the company as a precaution. Because if you get sick you cannot work.”

Enabling/Impeding

Personal/Family Resources

Within the second component of the Andersen Model, participants discussed the role that personal, family, and

community resources play in predicting HBV-specific health services.

With regards to family resources, participants discussed how family can serve as both a potential space for the expression of stigma, or as an important source of social support. One 29 year-old Malian man stated,

In the eyes of a family with a person with hepatitis B, hepatitis B equals AIDS. If a family member is sick, the family no longer has the same image in the community. The community may say that someone who died because of the disease belongs to this family, and so in some cases the whole family will be rejected. So, you must know your family well, and if it has a good level of understanding, it can treat you normally.

Additionally, participants identified fear of cost associated with seeking care and, as described above, fear of deportation as impeding factors. As one 24-year-old Malian man stated:

“There are people (immigrants) in an irregular situation who are afraid to get tested. Because for them they have been detected with the disease, the U.S. government will return them to their respective countries.”

Community Resources

Within the theme of community resources, participants described the important role of social communication networks in increasing access to information necessary to access care. One 38-year-old Senegalese woman described how she first heard about the African community center where she was tested for HBV: “Frankly, it was my sister in Senegal who told me that I can get care here [at the African community organization].”

This same woman emphasized the importance of having a culturally-appropriate source of care to further enable access: “It is important that people are aware that there is a structure that deals with Africans and that they can obtain information there.”

Others described the role that information technology can play in increasing access to information necessary to access care, as stated by a 43-year-old Senegalese man:

When I went on Google last night, I discovered that there isn't only just hepatitis B and C. I saw that there are other forms as well: E, F, I don't remember exactly which ones anymore. I wanted to print all this but I do not have a printer at home.

In addition to the sub-themes of family, fear of deportation, access to information technology, and the

availability of culturally appropriate sources of care, which were all identified by focus group participants within the enabling/impeding domain, the advisory group also identified insurance status and income. Specifically, undocumented immigrants are ineligible for health insurance under the Affordable Care Act, thereby posing an additional impediment to accessing care. Many members of this community are also employed in service industry positions including work as taxi drivers or in hair braiding salons that do not provide insurance or pay a high enough salary to cover the potentially high costs of care in the US medical system.

Need

Perceived Need

Within the need domain, participants emphasized that HBV's long latency period during which an affected person may have no overt symptoms can create a false perception of good health thereby making the person less likely sense a need to seek care. As one 55 year-old Malian woman stated:

To get people to test, you should let them know that you can sleep with the virus without knowing it – without ever knowing that you have it. You can be healthy and feel absolutely nothing. Generally when you develop signs, like a bloated belly, it is already too late. So if the message is that people go and get tested to detect it before it gets to this point, you will catch the disease in its early stages and can get treatment.

Discussion

Through four focus groups with 39 participants we explored predisposing/discouraging, enabling/impeding, and need factors that affect francophone West African immigrants' access to HBV medical care. Integral to this process, we also identified potential modifications to the Andersen Model specific to this community.

To better understand the generalizability of our results, it is necessary to compare the study's participant demographics to those of the West African immigrant population in NYC. The majority of the study participants came from West Africa, with the exception of one participant from Cameroon (Central Africa), were male, and in their late 30's. These general attributes approximate the broader trends of African immigrants in NYC, who are also predominantly from West Africa, male, and of working age (between 16 and 64) [1, 30].

In contrast, this study population likely differs in its access to HBV services from that of the general population of African immigrants in NYC in that half reported prior HBV screening. This high rate of prior screening is likely attributable to an HBV screening program that had begun at the community organization where the focus groups were held, and to which many of the participants were connected in some way [9]. This inclusion of participants who had previously been screened sheds light on facilitating factors in addition to barriers.

Among predisposing determinants of access to care, gender and age warrant a brief separate discussion. Regarding gender, being a woman increases the chances of HBV screening as this test is part of routine prenatal care in the US. Similarly, infants have been routinely immunized against HBV since 1992, and in New York State, vaccination is required for entry into middle school [34]. Additionally, newborn children of mothers with HBV have been recommended to receive HBV vaccination and immune globulin since 1984 [37]. Both groups, pregnant women and children, also have access to public insurance regardless of immigration status, whereas non-pregnant adults do not. Interestingly, although gender and age are immutable “biological imperatives” within the predisposing category of the Andersen Model, [5] they do not automatically lead patients to be linked to care as was demonstrated by a recent study in the Bronx, NYC, among women with HBV (88 % of whom were West African) half of whom reported never having heard of HBV despite having been recently diagnosed and despite a New York State Department of Health program that contacts all women with HBV [33, 36].

Thus, although demographics such as age and gender are immutable, their effect on predisposing patients’ to accessing care appears to be intricately connected to other factors in the Andersen Model including health beliefs and social structure. Among health beliefs, four sub-themes emerged from the focus groups: knowledge, fatalism, stigma, and attitudes towards health services. Rather than discussing each of these sub-themes in depth, the focus groups highlighted their interdependent relationships. Participants described how limited knowledge of opportunities for vaccination and treatment can contribute to fatalism. They also discussed the complex relationship between knowledge and stigma with some participants arguing that stigma would decrease with knowledge, whereas others felt that awareness of HBV’s potential sexual transmission could increase stigma and related confidentiality concerns. Prior studies that have examined the relationship between knowledge, stigma, and screening or other measures of access to care with some supporting the position that stigma decreases, screening rates and access to care increase with greater knowledge, [13, 21, 28, 38] whereas others warn against potential unintended consequences of increased stigma through awareness raising

campaigns [45]. Although it is clear that increased knowledge is called for in this community regarding HBV, the divergent positions, both in the focus groups and the literature, highlight the need to increase knowledge in a culturally sensitive way.

Similarly, within the enabling and impeding category, participants discussed the varied roles personal and family resources may play in affecting access to care. For example, participants discussed both the enabling role that family may play by providing social support, but also the potentially impeding effect families may exert by reinforcing stigma. This fear contrasts with findings among Chinese immigrant communities that having a family member with HBV is associated with lower levels of stigma [12].

The original Andersen Model groups social structure into a separate domain from health beliefs, but the focus group participants in this study discuss factors within each domain together. They describe how religious social establishments can have an important effect on health knowledge, attitudes, and values. For this exclusively Muslim population, participants described how religion can either serve as a source of information on opportunities to access care, or as a medium through which fatalism and stigma are expressed. Religion’s dual and conflicting role has also been described in sub-Saharan African settings, particularly with regard to mental illness [25] and HIV [7, 17]. These papers highlight the complex relationship between religion, knowledge, and attitudes towards seeking care—and the focus groups in this study are suggestive of the intersecting roles that this predominantly Muslim faith community, access to information, fatalism, and stigma all play in shaping individual behavior.

Besides discussing health beliefs and social structure as predisposing/detering factors, focus group participants also expressed concerns regarding impeding factors including deportation as a consequence of interacting with the medical system. Similar fears have been documented among undocumented immigrants presenting to the emergency room [29]. Undocumented immigrants have also been found to use medical services less than their documented counterparts [10], and report significant barriers to accessing medical care due to their undocumented status [2, 20].

The perception of cost was another potentially impeding sub-theme discussed in the focus groups. The medication used to treat HBV can cost over \$30,000 per year, which does not include laboratory, radiology, and physician fees [15]. With undocumented immigrants ineligible for insurance under the Affordable Care Act [39], the cost for HBV will pose a significant barrier to ongoing monitoring or needed treatment without expansion of patient assistance programs. This lack of public funding for screening, vaccination, and treatment for high-risk immigrant communities such as those described in this study stands in contrast

to the cost-effectiveness of providing these services [24, 41].

In contrast, enabling factors discussed by focus group participants included information technology and the Internet. Although access to the Internet is not equal across demographic groups and is often lower among minority groups [11], these same groups may rely more heavily on the Internet to access health information to offset other disadvantages resulting from lack of social capital [31]. Thus, the Internet is a potentially important means of disseminating information on HBV and opportunities to access care.

In addition to the Internet, participants discussed the role that word-of-mouth, communication networks, and gatekeepers plays in enabling access to care. The importance of social networks in increasing the likelihood of an individual accessing care have been extensively described with regards to HIV, [14, 26, 40] and the close-knit nature of the African immigrant community is another potential important enabling factor in increasing access to HBV services in NYC.

This study provides detailed qualitative insight into francophone West African immigrants' perceptions of factors affecting access to HBV services in NYC and employs these perceptions to develop a modification of the Andersen Model specific to this community. The result yields an adaptation of the Andersen Model that emphasizes the fluid and recursive nature of the model and the interdependent relationships of its different domains and categories. In this iteration, the relationship between the predisposing/discouraging, enabling/impeding, and need categories is emphasized as the interdependence of the individual domains within each category. Health belief shape and are shaped by social structure, which interact closely with personal/family and community resources, all of which influence perceived need. Andersen himself emphasizes the recursive nature of the model in its most recent iteration, [5] and this study describes the specific qualitative relationships between the model's domains as they relate to the West African immigrant population in NYC. The detailed qualitative understanding of factors effecting access HBV services in this community that this study provides will hopefully facilitate ongoing efforts to increase screening and linkage to and maintenance in care that is being led by many community organizations, academic institutions, and government programs.

Conclusion

Using the Andersen Model, we explored francophone West African immigrants' perceptions of predisposing/discouraging, enabling/impeding, and need factors as they relate to HBV services. The results highlight the importance of increasing knowledge of HBV and opportunities to

access care in a culturally-sensitive manner that addresses fatalism without exacerbating stigma. The study also suggests working with religious establishments, using the Internet, relying on social networks to disseminate information, and addressing fears of detention and/or deportation. Questions regarding cost and health insurance were also raised in the study, and will be need to be addressed in providing HBV services to undocumented immigrants who are not eligible for insurance under the Affordable Care Act. Finally, this study proposes a qualitative modification of the Andersen Model that emphasizes the interdependent relationships between its different domains that hopefully will be relevant in facilitating deeper understandings of factors affecting access to care in other minority communities.

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