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Barriers to Linkage to Care for Hepatitis B Virus Infection: A Qualitative Analysis in Burkina Faso, West Africa

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Abstract. Hepatitis B virus (HBV) infection is a critical global health problem. The World Health Organization (WHO) has recently developed a global elimination strategy for HBV infection. Increasing access to screening, liver assessment, and antiviral treatment are crucial steps in achieving this goal. Little is known, however, about obstacles to linkage to care in low- and middle-income countries. Using a grounded theory approach, this qualitative study sought to characterize the diagnostic itineraries of people with chronic HBV infection in Burkina Faso, a west African country with high HBV prevalence, to identify barriers to linkage from screening to specialist care with hepatic assessment (alanine transaminase and hepatitis B e antigen or HBV DNA). We conducted 80 semistructured interviews with chronically infected people, their families, medical personnel, and traditional practitioners, and participant observation of HBV diagnostic announcements and consultations. Of 30 individuals diagnosed with chronic viral hepatitis, 18 inadvertently discovered their status through blood screening and 12 actively sought diagnosis for their symptoms. Only a quarter (8/30) were linked to care. Barriers included: 1) patients' ability to pay for testing and treatment; 2) a formal health system lacking trained personnel, diagnostic infrastructures, and other resources; 3) patients' familial and social networks that discouraged access to testing and HBV knowledge; 4) a well-developed demand for and provisioning of traditional medicine for hepatitis; and 5) a weak global politics around HBV. More training for medical personnel would improve linkage to care in sub-Saharan Africa. Developing effective communications between medical workers and patients should be a major priority in this elimination strategy.

INTRODUCTION

Hepatitis B and its lethal consequences are critical global health problems, with 2 billion people worldwide infected, 240 million suffering from chronic infection with hepatitis B virus (HBV), and over 780,000 deaths annually from its complications, liver cancer, and cirrhosis.¹ Sub-Saharan Africa is disproportionately afflicted, with more than 8% of the population suffering from chronic HBV infection. Although all African countries now include the hepatitis B vaccine in their Expanded Programs on Immunization, people infected prior to this inclusion face a high risk of developing chronic liver disease.² High HBV prevalence contributes to sub-Saharan Africa's elevated liver cancer rate.³ HBV's deleterious effects on the liver can be controlled through antiviral treatments, which often necessitate lifelong administration. For those infected, full hepatic assessment to measure the degree of liver inflammation, fibrosis, and HBV replication is a crucial step in determining indications for antiviral therapy.

Recent World Health Organization (WHO) *Guidelines for the Prevention, Care and Treatment of Persons Living with Chronic Hepatitis B* also recognize barriers of cost and accessibility to screening, hepatic assessment, and treatment of people with HBV, especially in sub-Saharan Africa.¹ There, cost and access are thought to be important barriers to linkage to care, from screening for hepatitis B surface antigen (HBsAg) to hepatic assessment, and from hepatic assessment to antiviral therapy.^{4,5} Other factors, however, may also contribute, including medical pluralism (concurrent or alternating

use of allopathic and traditional medicines) and the influence of social networks on chronic carriers' decision-making processes in low-resource, sub-Saharan African countries.^{6–8} Qualitative methodologies eliciting narratives of chronic HBV carriers can highlight critical, additional factors that impede linkage to HBV care in sub-Saharan Africa.

To our knowledge, very few anthropological studies examining chronic HBV carriers and linkage to care barriers in sub-Saharan Africa have been published.^{9,10} Other publications evaluate health worker and patient knowledge of HBV in African hospitals and barriers to screening and linkage to care among African immigrants to Europe and North America.^{11–14}

Consequently, we conducted a qualitative study to investigate barriers to full diagnosis and linkage to care from screening to hepatic assessment among chronic HBV carriers in Burkina Faso, where HBsAg prevalence is very high (12.0%, 95% confidence interval = 11.7–12.4%).¹⁵ Drawing from WHO guidelines and common gastro-hepatological practice in Burkina Faso, we defined “hepatic assessment” as consulting a medical specialist and undergoing tests for alanine transaminase and hepatitis B envelope antigen (HBeAg) or HBV DNA, which are minimally required for evaluating treatment eligibility.¹

MATERIALS AND METHODS

Study setting. Burkina Faso is one of the world's poorest countries, with a Human Development Index ranking it 183rd out of 188 countries. Poverty affects access to health care, individually and regionally. Those who cannot pay for testing and care are excluded, and poor, rural regions have less medical infrastructure and fewer qualified health workers than wealthier urban ones.^{16,17} Because urban areas have screening and some diagnostic capacities for HBV, we conducted this

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research in the three largest cities: Ouagadougou (population 2.3 million), Bobo-Dioulasso (population 537,000), and Banfora (population 93,000).¹⁸ These urban populations are multi-ethnic and multilingual, although French and the national languages, Dyula and Mossi, dominate clinical consultations.

Burkina Faso's health-care system is organized around primary care clinics, regional and national structures. Patients initially seek consultations in primary care clinics, but are referred to regional hospital centers for more complex conditions. Burkina Faso's three national teaching hospitals in Ouagadougou and Bobo-Dioulasso accept referrals from regional hospitals and deliver specialized care.

Medical facilities are distributed unequally, posing barriers of geographical access and cost for any diagnosis and treatment. Of our three research sites, the Cascades region (Banfora) suffers the greatest dearth of medical structures, personnel, and resources, with only one regional hospital and 60 primary clinics. The Haut Bassin region (Bobo-Dioulasso) possesses better medical infrastructure, with one teaching hospital and 138 primary clinics. The Center region (Ouagadougou) has two teaching hospitals, five surgical clinics, and 113 primary clinics.¹⁹ Diagnostic testing (hematology, biochemistry, HBsAg, HBeAg, HBV DNA, liver ultrasound, and rarely, liver biopsy) and treatment of viral hepatitis are available in public structures in Ouagadougou and Bobo-Dioulasso²⁰; private clinics also offer more limited assessment services (HBeAg and liver ultrasound). In Banfora, patients receive HBsAg and HBeAg testing. A Bobo-Dioulasso physician conducts liver ultrasonography there once weekly, but patients must travel to Bobo-Dioulasso for HBV DNA testing and specialist consultations. The total cost of these tests, excluding biopsy, varies but can exceed 125,000 FCFA (US\$209).

"Traditional medical practitioners" are important and numerous providers of informal medical care. They range from pharmacists to local healers, use diverse diagnostic tools and prescribe plant- or animal-based therapies. Ouagadougou annually hosts the International Fair of Natural Remedies (SIRENA), attracting west African practitioners to promote their treatments for HBV and other disorders.

Our research occurred within a global and national context of political change around viral hepatitis. In March 2015, the WHO produced its first "Guidelines" for people with chronic HBV, marking a major advance in the global health response to this problem. In Burkina Faso, an expanding political mobilization around viral hepatitis occurred during our research. Patients' associations organized in Ouagadougou and Bobo-Dioulasso, advocating for increased attention to viral hepatitis and the provision of medical support for chronic carriers. Association leaders, gastroenterologists, and ministry officials also drafted a national plan for the screening, diagnosis, and treatment of viral hepatitis, but governmental changes since October 2014 have delayed action on it.

Data collection. We conducted this study during research trips between 2012 and 2014. Armande Sanou, Issiaka Bamba, and Abdoulaye Traoré reside part-time in the study sites and have deep sociocultural knowledge of their populations. We collected our data using in-depth individual interviews, informal discussions, and participant observation.

We pursued 30 semistructured, individual interviews with people with viral hepatitis. Participants were included if they had received a diagnosis of chronic viral hepatitis. Because many people in Burkina Faso have never undergone screen-

ing and do not know if they are infected with viral hepatitis, we used purposive sampling with registers located in Bobo-Dioulasso and Ouagadougou blood centers, patient associations, traditional medical practitioners recognized for their hepatitis treatments, and the Sourou-Sanou hospital (Bobo-Dioulasso). The interview process relied on interview guides, pretested during a feasibility study conducted in 2010–2011. These interviews focused on local diagnostic categories related to "liver sickness," subjective experiences of illness and its consequences, diagnostic processes, referrals, and therapies (Table 1).

We interviewed six family members of people with viral hepatitis. Relying on purposive sampling, we asked participants with a viral hepatitis diagnosis if they would permit us to interview one or more family members. Interviews addressed their subjective experiences of the chronically infected family member's illness and its consequences.

We led 25 interviews with gastroenterologists, general practitioners, nurses, and medical authorities at the Banfora, Bobo-Dioulasso, and Ouagadougou hospitals and blood centers. We selected participants if they interacted professionally with viral hepatitis patients. Interviews addressed knowledge of viral hepatitis, challenges of screening disclosures, testing, monitoring, and treatment of viral hepatitis patients.

We conducted four interviews with hepatitis association leaders, referred to us through Ouagadougou gastroenterologists. Interviews addressed challenges facing those diagnosed with chronic viral hepatitis.

We led four interviews with people undergoing viral hepatitis screening at the World Hepatitis Day in July 2013. These participants were randomly selected at the screening site. Interviews focused on knowledge of HBV and hepatitis C virus (HCV) and reasons for undergoing screening.

Through conversations with medical personnel and participants, we identified 11 traditional medical practitioners who treated viral hepatitis. Interviews addressed practitioners' knowledge and explanations of hepatitis, local terminology for HBV and HCV, and treatment of viral hepatitis patients.

All interviews, lasting between 45 and 90 minutes, were conducted and recorded in French, Dyula, Mossi, or Goin. Recordings were transcribed verbatim and if not conducted in French, were translated into French. Accuracy of interview transcriptions and translations were verified by Issiaka Bamba.

We conducted participant observations and took detailed notes of diagnostic announcements at two blood centers, the 2013 World Hepatitis Day in Ouagadougou, the west African International Fair of Natural Remedies, and patient consultations with one gastroenterologist and with traditional medical practitioners. We also conducted and took detailed notes of informal discussions with medical workers and HBV patients.

Ethical approvals. The Institut Pasteur Institutional Review Board and the Burkina Faso Committee for Health Research Ethics evaluated the protocol and informed consent form and provided ethical approvals for this study. All participants received and signed an informed consent form.

Qualitative data analysis. To understand barriers to achieving linkage to care, we used a grounded theory approach. This approach convened best to our aims of understanding HBV, diagnosis, and treatment from multiple participants' perspectives, especially those of chronic carriers.²¹

TABLE 1
Individual interview sample questions

Patient interviews
Explain to me when you first began to suspect that you were ill. Under what circumstances and how did you obtain a diagnosis? When the health care worker announced your screening/diagnostic results, what exactly did s/he tell you? Did s/he explain its transmission? Its consequences and treatment? Did s/he refer you to another medical worker? Whom? How did you respond to this announcement? For you, what is hepatitis B? If you had symptoms, what did you do to relieve or to treat them? Do you have symptoms now? Did you share your (screening or diagnostic) results with anyone? Whom? Are you undergoing treatment currently? Why or why not? (Explain) What consequences has your screening or diagnostic result had on your life?
Family members of patients living with HBV
Tell me about how you discovered that your family member had hepatitis B. (If family member was ill, explain steps taken to identify illness). Before this result, had you heard of HBV? What did you know of it? How did this family member explain to you his/her condition? How do other people (other family members, friends, neighbors) understand his/her condition? What term is used in your local language to describe HBV? Does your family member have symptoms now? (Explain) How has this diagnosis affected your family member's life? How has it affected your life?
Traditional practitioners
For which illnesses do you most commonly treat patients? Do you specialize in a particular population or a particular illness? How did you acquire your knowledge about illnesses and their treatments? For you, how does a person fall ill? Are you aware of any illnesses that are asymptomatic during childhood but manifest themselves later in life, during adulthood? Have you heard of hepatitis or hepatitis B? What term(s) do you use to refer to it in your local language? Explain to me how you diagnose someone with hepatitis B. What treatment do you provide for someone with HBV? Are there certain life practices that HBV patients should follow?
Medical workers
If you were to explain hepatitis B in very simple terms to a patient who knew nothing about it, how would you do so? What local language term(s) would you use? How would you describe its transmission, symptoms, screening and diagnosis, treatment and prevention? Do you ever see cases in which you suspect hepatitis B? Why might you suspect HBV? What do you do in such a case? How do you think that the patients you see understand HBV? In your experience, what happens to patients after they receive a positive screening result for HBV? Do they follow through with other diagnostic tests? Why or why not? Have you referred patients to a traditional medical practitioner? Do you provide treatment of people diagnosed with HBV? Are there certain life practices that HBV patients should follow? What is the most difficult aspect of your medical work that pertains to HBV?

HBV = hepatitis B virus.

Tamara Giles-Vernick and Fabienne Hejoaka developed codes and transferred translated interviews and notes into NVivo (version 10) qualitative analytical software. After initial line-by-line coding, we discussed and reorganized

codes to synthesize and compare larger data segments.²¹ We recoded all transcripts and notes, evaluated results generated by coding and the relationships between data, codes, and analytical categories. Local theories of hepatitis and logics underpinning participants' decision-making emerged from this analysis.

Several strategies ensured rigorous data collection and analysis. We interviewed wide-ranging informants implicated in HBV screening, diagnosis, and treatment, to generate comparisons across diverse participants' experiences. We triangulated qualitative evidence with published biomedical literature on HBV and discussions with viral hepatitis specialists for insight into HBV's natural history and epidemiological risks in sub-Saharan Africa. Finally, we presented our study results in 3-day-long workshops to health workers and patients' associations in our study sites.

Statistical analysis. We estimated the proportion of participants with chronic viral hepatitis who were successfully linked to care. We used Fisher's exact test to examine the association between potential determinants and linkage to care, considering $P < 0.05$ to be statistically significant. We did not perform multivariable analysis because of the small sample size.

RESULTS

We conducted a total of 80 interviews and 22 hours of participant observations of consultations and screening announcements. We recruited 30 patients in the following sites: blood centers in Bobo-Dioulasso and Ouagadougou ($N = 16$), patient associations ($N = 9$), traditional practitioners ($N = 4$), and the Sourou-Sanou hospital ($N = 1$). Of our 30 interviewees with chronic hepatitis (Table 2), 21 (70%) were men, and the median age of participants was 32.5 years (interquartile range = 25–43). All patients had a diagnosis of chronic hepatitis: 27 with HBV, two with HCV, and one with HBV and HCV. Although our primary concern was with chronic HBV carriers, we included participants diagnosed with HCV in our results. Approximately one-quarter of participants (8/30) were linked to care for hepatic assessment. The following variables were found to be statistically associated with a linkage to care (Table 3): the site of screening disclosure, referral to a specialist, and information about antiviral therapies at the screening disclosure. Our qualitative analysis explains how and why these and other factors shaped participants' linkage to care.

Circumstances and sites of screening. Informants underwent screening for HBsAg for multiple reasons and in diverse contexts. This screening is widely available in Ouagadougou and accessible in the Banfora hospital and the Bobo-Dioulasso hospital, blood center, and some diagnostic laboratories. Blood donors are screened free of charge.

Whether informants experienced symptoms influenced their initial screening path. Among those without symptoms ($N = 21$), 18 discovered incidentally through blood donations that they carried HBsAg. One voluntarily participated in screening World Hepatitis Day, and two others sought screening after a family member received an HBV diagnosis. One woman explained, "My husband had [HBV]. He died from it. Just before he died, he asked me to...take a test. Because I didn't know this sickness... And when I did [she whispers], it was positive."

TABLE 2
Patient characteristics

No.	Sex	Age	Marital status*	Education levels	HBV or HCV	Study recruitment site	Year screened	Screening circumstance	Screening disclosure site	Advised at screening to undergo further liver assessment? Advice	Hepatic assessment	Antiviral therapy	Traditional medicine
P1	F	25	Single	Secondary	HBV	Blood center	2013	Blood donation	Blood center	No	No	No	No
P2	F	40	Widow	Middle school	HBV	Blood center	2011	Spouse died of HBV	Blood center	Avoid fat, alcohol No Informed that she had "liver cancer"	No	No	No
P3	M	33	Married	Secondary	HBV	Blood center	2011	Illness	Blood center	No Referred to TP; avoid fat	No	No	Yes
P4	M	56	Married	Primary school	HBV	Blood center	2013	Blood donation	Blood center	No Avoid alcohol, sugar	No	No	No
P5	M	20	Single	Secondary	HBV	Blood center	2012	Blood donation	Blood center	No Avoid alcohol, sugar	No	No	No
P6	F	40	Married	None	HBV	Traditional practitioner	2010	Illness	Hospital	No	No	No	Yes
P7	M	20	Single	Secondary	HBV	Blood center	2012	Blood donation	Blood center	No	No	No	No
P8	F	32	Married	Postsecondary	HBV	Association	2008	Neonatal death	Hospital	Yes	Yes	No	No
P9	M	25	Single	Secondary	HBV HCV	Blood center	2010	Blood donation	Blood center	No No treatment existed; avoid fat, cigarettes, alcohol	No	No	Yes
P10	M	26	Single	Secondary	HBV	Blood center	2012	Blood donation	Blood center	Yes Referred to TP; avoid fat, pork, alcohol	No	No	Yes
P11	M	30	Married	Middle school	HBV	Blood center	2013	Blood donation	Blood center	No	No	No	No
P12	M	43	Married	Middle school	HBV	Association	2008	Blood donation	Blood center	Yes	Yes	Yes	Yes
P13	F	49	Single	Post-secondary	HBV	Association	2003	Blood donation	Blood center	No	No	No	No
P14	M	47	Married	Primary	HBV	Association	2010	Illness	Hospital	Referred to TP Yes	Yes	Yes	No
P15	M	29	Single	Postsecondary	HBV	Association	2011	Blood donation	Blood center	Stopped because lacked funds	Yes	No	No
P16	M	34	Married	Postsecondary	HBV	Association	2013	Blood donation	BC in Hospital	No No Avoid fat, alcohol	Yes Yes	Yes	Yes
P17	F	22	Single	Secondary	HBV	Blood center	2013	Blood donation	Blood center	No Avoid fat	No	No	Yes
P18	F	40	Married	None	HBV	Traditional practitioner	2008	Illness	Clinic	No	No	No	Yes
P19	F	45	Widow	Primary	HBV	Traditional practitioner	2008	Illness	TP	Referred to TP No	No	No	Yes
P20	M	23	Single	Secondary	HBV	Blood center	2011	Blood donation	Blood center	No	No	No	No
P21	M	36	Non-marital alliance	Secondary	HBV	Traditional practitioner	2007	Illness	TP	Referred to TP No	No	No	Yes
P22	M	24	Single	Postsecondary	HBV	Blood center	2010	Blood donation	Blood center	No Avoid alcohol, fat, cigarettes	No	No	Yes

(continued)

TABLE 2
Continued

No.	Sex	Age	Marital status*	Education levels	HBV or HCV	Study recruitment site	Year screened	Screening circumstance	Screening disclosure site	Advised at screening to undergo further liver assessment? Advice	Hepatic assessment	Antiviral therapy	Traditional medicine
P23	M	56	Married	Secondary	HCV	Association	2009	Illness	Hospital	Yes	Yes	Yes	No
P24	M	43	Single	Postsecondary	HBV	Blood center	2011	Blood donation	Blood center	N	No	No	Yes
P25	F	30	Married	Primary	HBV	Hospital	2003	Illness	Company clinic	No	Yes	No	Yes
P26	M	21	Single	Secondary	HBV	Blood center	2013	Blood donation	Blood center	No	No	N	No
P27	M	29	Married	Primary	HCV	Blood center	2013	Blood donation	Blood center	No	No	N	No
										Avoid alcohol, fat, sugar			
P28	M	55	Married	Middle school	HBV	Association	2014	World Hepatitis Day	World Hepatitis Day	Yes	Yes	N	No
P29	M	22	Single	Secondary	HBV	Blood center	2012	Blood donation	Blood center	No	No	No	Yes
										Avoid alcohol, fat, cigarettes			
P30	M	37	Married	Postsecondary	HBV	Association	2014	Illness	Clinic	Yes	No	No	Yes
										No treatment existed			

HBV = hepatitis B virus; HCV = hepatitis C virus; TP = traditional practitioner.
*-"Single" denotes not currently married.

For people experiencing illness ($N = 9$), pathways leading to an HBV screening could be convoluted. One man suffering from fatigue, low-grade fever, and abdominal pain, recounted

[The health clinic] made me do all sorts of tests and found nothing. They prescribed vitamins. I paid for them and took them, but the symptoms came back two days later. I took medicines and felt a little better, but afterwards the symptoms returned ... I went to the hospital, nothing. I went to traditional healers, they gave me medicines, but these didn't work.

He therefore donated blood, thinking that the blood center would defer him if he was ill.

Screening could occur months after the onset of symptoms because informants initially explained their symptoms in other ways. Five informants self-diagnosed, explaining their symptoms in the Dyula language as “sumaya,” “sumaya ba” (“severe sumaya”), or “djokadjo” (a severe illness sometimes associated with the manipulation of occult forces). “Sumaya” is part of a semantic network used throughout west Africa to denote malaria-like illnesses associated with fever, humidity, and coolness.^{22,23} Medical personnel also use these terms in health-care settings.

When symptoms persisted, family members and friends intervened, theorizing about the cause of illness and bringing informants to a formal or informal health workers or diviners. Frequently, such explanations involved the use of occult forces and human immunodeficiency virus (HIV). The brother of a long-suffering Banfora woman brought her to two diviners, who concurred that her illness resulted from a family member's malediction. As her symptoms persisted and her neighbors whispered that she was infected with HIV, another brother arranged a consultation with a local physician who ordered an HBsAg screening.

Screening disclosure at blood centers and low-cost screening sites. The screening disclosure site and content strongly affected informants' linkage to care (Table 3). Donors were supposed to receive screening results by visiting the blood center 2 weeks after donation, attending a prescheduled consultation, or after receiving a call from the blood center to retrieve results. The World Hepatitis Day screening provided results onsite.

Many informants found blood center disclosures brief, confusing, and wrenching. A health worker would usher the donor into a private room and rapidly explain the screening results. One woman insisted that the medical worker disclosing her result said that she had “liver cancer,” although she had undergone no other tests. Eleven recalled that they learned little or nothing about transmission, referrals, diagnostic testing, or treatment. Eight others heard erroneous information about transmission, its consequences, and possibilities for treatment. Ten recalled advice to avoid fatty foods, coffee, cigarettes, and alcohol; one concluded that dietary restrictions would “cure” her, and two others believed that fatty foods “brought on” or “transmitted” the virus. Only two participants reported receiving advice to consult a specialist and undergo additional testing; six others were referred to traditional practitioners. One young woman explained, “I tried to find out more information from the counselor at the blood bank ... I asked, what should

TABLE 3
Factors associated with a linkage to care

Variables		Proportion	P value (exact test)
Sex	Male	29% (6/21)	0.5
	Female	22% (2/9)	
Age group	20–30	14% (2/14)	0.2
	> 30	38% (6/16)	
Education	No secondary	36% (4/11)	0.3
	Secondary or above	21% (4/19)	
Year screened	2003–2010	42% (5/12)	0.1
	2011–2014	17% (3/18)	
Motivation for screening	Passive	17% (3/18)	0.1
	Active	42% (5/12)	
Place of screening result disclosure	Traditional healer	0% (0/2)	0.04
	Blood centers	15% (3/20)	
	Hospitals/clinics	57% (4/7)	
	World Hepatitis Day	100% (1/1)	
Told of antiviral therapy at screening disclosure	No: told that no treatment exists	0% (0/5)	0.002
	No: patient told nothing	19% (4/21)	
Told of liver specialist at screening disclosure	Yes	100% (4/4)	0.001
	No	9% (2/22)	
	Yes	75% (6/8)	
Told of traditional healer or medicine at screening disclosure	No	36% (8/22)	0.07
	Yes	0% (0/8)	

I do? He said no, it cannot be cured ... but he knew a healer ... selling an herbal product [for HBV] that he could find for me.”

Five donors who had not retrieved their screening results attempted donating blood again, but were informed publicly of their screening results by a secretary.

Screening disclosure at clinics. For those with symptoms who sought diagnosis at medical clinics ($N = 6$), screening disclosures were more likely to result in linkage to care. Four received advice to consult a gastroenterologist and obtain further testing; they eventually obtained hepatic assessment, except for one, who recounted that because the clinic nurse insisted that no treatment of HBV existed, he opted against consulting a gastroenterologist. Another participant, tested at a hospital where the hepatitis association president worked as a technician, benefited from a detailed screening disclosure. Two other patients were simply handed their laboratory reports, with no explanation at all; they eventually consulted a traditional practitioner.

Observed disclosures underscored difficulties that poorly trained medical personnel encountered in communicating about chronic HBV carriage. Health workers sometimes conveyed erroneous or potentially stigmatizing information, describing HBV, for instance, as a “hereditary illness,” but failing to explain that much transmission occurred in early childhood. Another health worker congratulated accepted donors on their “clean blood” and “clean living,” indirectly promulgating moralizing messages about positive screening results. Many health personnel found screening disclosures difficult because they knew little of HBV, how to communicate about it, nor to whom to refer patients.

Disclosure interpretations. Patient interpretations of screening disclosures were mixed. Most informants feared

the illness’s potentially fatal consequences, closely associating HBV with HIV/acquired immunodeficiency syndrome (AIDS). Over half of our participants (16/30) mentioned HIV, contending that HBV was “worse than HIV” because they believed that HBV was transmissible to other adults with whom they lived through kissing or sharing eating utensils. Six adopted excessive precautions, including using separate glasses, to protect other adults from their infection. Others feared that they would suffer physical symptoms and stigmatization of people with AIDS. One student called HBV “the little brother of HIV. It’s an illness that cannot be treated. If you have hepatitis B, it’s as if you have AIDS.”

Participants expressed anxiety about their futures. Some worried whether they develop liver problems. One high school student admitted, “The announcement was so brutal ... I was already digging my grave.” Others were troubled that they might infect family members, or that their illness would have detrimental material and emotional consequences. A Bobo-Dioulasso widow worried about who would care for her children if she died: “If this sickness takes me,” she confessed, “it will be difficult for my children.”

What happened after a screening disclosure? Eight participants obtained linkage to care and hepatic assessment. Of these participants, five recalled guidance to consult a specialist and obtain hepatic assessment; three others never received this advice, but nonetheless pursued full diagnosis. Three fully evaluated participants required only long-term monitoring; two continued monitoring, whereas the third abandoned it because of cost. Four other patients with full assessment received treatment, amounting to US\$54/year in 2014 for tenofovir, and US\$23/year for lamivudine: three patients received treatment of HBV, and one for HCV. One HBV patient stopped his lamivudine treatments a year before we interviewed him because monitoring and treatment were too costly. Treatment costs dropped considerably during our research, but these medications remained free of charge to people diagnosed with HIV.

The vast majority of participants (22/30) had no linkage to care. Seven expressed concerns about the cost of testing, monitoring, or any treatment, including traditional. Five were discouraged from seeking biomedical treatment because medical workers asserted that no allopathic HBV treatment existed.

Traditional medicine had a noticeable effect on participants’ postdisclosure decisions. Overall, 15 participants had ever taken traditional viral hepatitis remedies. Two were under a traditional practitioner’s care before undergoing screening. Medical personnel counseled five participants at disclosure to consult traditional practitioners; three followed up with these practitioners. After their screening disclosure, 10 more sought traditional treatments, perceiving traditional practitioners as more available, less expensive, and more competent to treat HBV than biomedical physicians.

Traditional practitioners ordered biomedical testing, including HBsAg screening and HBV DNA assays, to evaluate their patients. They developed remedies for HBV or for multiple illnesses perceived as related. Because HBV was understood as one of several “liver sicknesses,” traditional remedies like “Hepatex” (containing *Cochlospermum planchonii* and *Chrsiantellum afroamericanum*) were prescribed for multiple ailments—“malaria, jaundice, hepatitis, and liver cirrhosis.” Prices varied, but could exceed 25,000 FCFA (US\$40)

per month; one informant spent over US\$1,600 in 1 year on such treatments.

Family members, friends, and acquaintances influenced participant linkage to care. Eleven were encouraged by family members or friends to consult traditional practitioners. Conversely, five informants acquainted with patients' association members and nondisclosing medical personnel received encouragement to seek more testing.

DISCUSSION

Our qualitative research revealed that nearly three-quarters of chronically infected interviewees with viral hepatitis did not achieve linkage to care with a specialist. Several factors prevented this linkage.

Our study shows that ability to pay is a barrier preventing linkage to care. Full diagnosis—an estimated US\$209—and treatment in a country where gross national income per capita in 2014 was \$700 and where 46.7% of the population lives below the national poverty line is very costly.²⁴

Our study confirms that access, broadly defined, is a significant barrier to linkage to care.²⁵ The formal health system in three cities lacked infrastructure and other resources for hepatitis screening and liver assessment. Equally important, many medical personnel lacked HBV knowledge, stymied by the virus's nonspecific symptomatology and the complex natural history of chronic infection. They conveyed erroneous information about transmission and available treatment, including that no treatment existed; failed to refer patients to specialists; and encouraged them to consult traditional medical practitioners. These messages strongly influenced whether patients pursued further testing. Hospitals, with better trained medical personnel, tended to encourage better linkage to care.²⁶

Patients' familial and social networks could function as barriers to full linkage to care. Family members, friends, and acquaintances (including medical workers) influenced participants to consult traditional practitioners, rather than specialists. Nevertheless, a relationship with knowledgeable health workers and hepatitis association members outside the screening disclosure site could propel them to seek full hepatic evaluation.

A well-developed traditional medicine that diagnoses and treats people with HBV and viral hepatitis constituted a barrier to linkage to care. Traditional remedies for viral hepatitis abound, and our participants demonstrated a strong demand for these services and products, perceived to be more available, effective, and less costly—even when they were not.

Finally, a weak global politics around HBV and viral hepatitis, in general, could pose a barrier to linkage to care. HBV is not included in the Global Fund for HIV, malaria, and tuberculosis to ensure free treatment and access to screening, testing, and monitoring, and Burkina Faso, like most sub-Saharan African countries, does not have a national program to control viral hepatitis. But patient associations are expanding HBV screening activities and advocating greater access to HBV monitoring and treatment in Burkina Faso.

HIV looms large in HBV health politics. Of course HBV and HIV differ, but their "material proximities"—certain symptoms, screening sites, and treatments—permitted our informants to understand HBV risks and consequences in

terms of HIV.^{27,28} Drawing from a historical politics around HIV testing and treatment, patient associations have justly advocated HBV inclusion in the Global Fund.

Our study differs from other studies of HBV in sub-Saharan Africa, in that we focus specifically on patients' diagnostic itineraries and the multiple barriers to linkage to care. The two other published qualitative studies in sub-Saharan Africa mention access to care as a problem, but neither addresses the problem in depth. One seeks to compare how Côte d'Ivoirians and African migrants in France characterized their infections and responded to their diagnostic announcements,⁹ whereas the other addressed a Ghanaian public's perceptions of the illness and its transmission.¹⁰

Our study has two limitations. Our sample was not representative of Burkina Faso's population. Study participants tended to come from wealthier, better educated families, thus reducing the importance of diagnostic costs in their itineraries. Our qualitative approach also relied on participants' recollections, which can be fallible. Patients may have received information about specialist referrals or treatments during their screening disclosures, but did not remember it. If so, medical personnel nonetheless needed to communicate more effectively so that patients recalled better this advice.

Linkage to care is a crucial step in reducing liver disease among chronic HBV carriers. We found that most participants receiving positive screening for viral hepatitis did not continue with further clinical assessment. The WHO guidelines facilitating the expansion of medical infrastructure and diagnostic technologies offer important recommendations to ensure linkage to care, but our results show that training health personnel is also critical. We have developed educational materials for medical workers responsible for screening disclosures, including an announcement guide explaining HBV biology and epidemiology, reasons for full diagnosis and monitoring, and specialists to consult. After translating the guide into Moore and Dyula languages, we will submit it to the Ministry of Health for official validation and eventual use in Burkina Faso health structures. More investment in training medical personnel to communicate better the risks, transmission, and need for testing, monitoring, and antiviral treatment of viral hepatitis would be crucial step in reducing liver disease among Africa's poorest populations.

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REFERENCES

- WHO, 2015. *Guidelines for the Prevention, Care and Treatment of Persons with Chronic Hepatitis B infection*. Geneva, Switzerland: World Health Organization. Available at: http://apps.who.int/iris/bitstream/10665/154590/1/9789241549059_eng.pdf?ua=1. Accessed March 16, 2015.
- Shimakawa Y, Lemoine M, Njai HF, Bottomley C, Ndw G, Goldin RD, Jatta A, Jeng-Barry A, Wegmuller R, Moore SE, 2015. Natural history of chronic HBV infection in west Africa: a longitudinal population-based study from The Gambia. *Gut*. [gutjnl-2015-309892](https://doi.org/10.1136/gutjnl-2015-309892).
- El-Serag H, 2011. Hepatocellular cancer. *N Engl J Med* 365: 1118–1127.
- Lemoine M, Eholié S, Lacombe K, 2015. Reducing the neglected burden of viral hepatitis in Africa: strategies for a global approach. *J Hepatol* 62: 469–476.
- Stockdale AJ, Geretti AM, 2015. Chronic hepatitis B infection in sub-Saharan Africa: a grave challenge and a great hope. *Trans R Soc Trop Med Hyg* 109: 421–422.
- Samuelsen H, 2001. Infusions of health: the popularity of vaccinations among Bissa in Burkina Faso. *Anthropol Med* 8: 163–175.
- Leach MA, Fairhead JR, Millimouno D, Diallo AA, 2008. New therapeutic landscapes in Africa: parental categories and practices in seeking infant health in the Republic of Guinea. *Soc Sci Med* 66: 2157–2167.
- Carruth L, 2014. Camel milk, amoxicillin, and a prayer: medical pluralism and medical humanitarian aid in the Somali Region of Ethiopia. *Soc Sci Med* 120: 405–412.
- Pourette D, Enel C, 2014. Représentations et vécu de l'hépatite B de patients subsahariens en Côte d'Ivoire et en France: représentations and disease experience of hepatitis B by Sub-Saharan patients in Ivory Coast and France. *Santé Publique* 26: 869–878.
- Mkandawire P, Richmond C, Dixon J, Luginaah IN, Tobias J, 2013. Hepatitis B in Ghana's upper west region: a hidden epidemic in need of national policy attention. *Health Place* 23: 89–96.
- Blanas DA, Nichols K, Bekele M, Shankar H, Bekele S, Jandorf L, Izzeldin S, Ndiaye D, Traore A, Bassam M, 2015. Adapting the Andersen model to a francophone west African immigrant population: hepatitis B screening and linkage to care in New York City. *J Community Health* 40: 175–184.
- Cheng A, Jose J, Larsen-Reindorf R, Small C, Nde H, Dugas L, Ehrhardt S, Nelson K, Ezeanolue E, Layden J, 2015. A survey study of pregnant women and healthcare practitioners assessing the knowledge of attitudes and practices of hepatitis B management at a teaching hospital in Kumasi, Ghana, west Africa. *Open Forum Infect Dis* 2: ofv122.
- Pourette D, 2013. Prise en charge du VIH et de l'hépatite B chronique chez les migrants subsahariens en France: le rôle-clé de la relation médecin-patient. *Santé Publique* 25: 561–570.
- Abeje G, Azage M, 2015. Hepatitis B vaccine knowledge and vaccination status among health care workers of Bahir Dar City Administration, northwest Ethiopia: a cross sectional study. *BMC Infect Dis* 15: 1.
- Schweitzer A, Horn J, Mikolajczyk RT, Krause G, Ott JJ, 2015. Estimations of worldwide prevalence of chronic hepatitis B virus infection: a systematic review of data published between 1965 and 2013. *Lancet* 386: 1546–1555.
- Ridde V, Carabali M, Ly A, Druetz T, Kouanda S, Bonnet E, Haddad S, 2014. The need for more research and public health interventions on dengue fever in Burkina Faso. *PLoS Negl Trop Dis* 8: e2859.
- Ridde V, 2008. "The problem of the worst-off is dealt with after all other issues": the equity and health policy implementation gap in Burkina Faso. *Soc Sci Med* 66: 1368–1378.
- INSD, 2013. *Population Des Principales Villes*. Available at: <http://www.insd.bf/n/contenu/Tableaux/T0314.htm>. Accessed December 20, 2015.
- INSD, 2013. *Annuaire Statistique. Ouagadougou: Ministère de l'Économie et des Finances*. Available at: http://www.insd.bf/n/contenu/pub_periodiques/annuaire_stat/Annuaire_stat_nationaux_BF/Annuaire_stat_2013.pdf. Accessed December 20, 2015.
- Bonnard P, Sombié R, Lescure F-X, Bougouma A, Guiard-Schmid JB, Poynard T, Calès P, Housset C, Callard P, Le Pendeven C, 2010. Comparison of elastography, serum marker scores, and histology for the assessment of liver fibrosis in hepatitis B virus (HBV)-infected patients in Burkina Faso. *Am J Trop Med Hyg* 82: 454–458.
- Charmaz K, 2006. *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London: Sage.
- Giles-Vernick T, Traore A, Sirima SB, 2011. Malaria, environmental change, and a historical epidemiology of childhood 'cold fevers': popular interpretations from southwestern Burkina Faso. *Health Place* 17: 836–842.
- Dugas M, Dubé E, Bibeau G, 2009. Translating malaria as sumaya: justified convention or inappropriateness? *Anthropol Med* 16: 307–318.
- World Bank, 2015. *World Development Report*. Available at: <http://data.worldbank.org/country/burkina-faso>. Accessed March 18, 2016.
- Gulliford M, Figueroa-Munoz J, Morgan M, Hughes D, Gibson B, Beech R, Hudson M, 2002. What does 'access to health care' mean? *J Health Serv Res Policy* 7: 186–188.
- Debes J, Kayandabila J, Pogemiller H, 2016. Knowledge of hepatitis B transmission risks among health workers in Tanzania. *Am J Trop Med Hyg* 94: 1100–1102.
- Fontein J, 2011. Graves, ruins, and belonging: towards an anthropology of proximity. *J R Anthropol Inst* 17: 706–727.
- Brown H, Kelly AH, 2014. Material proximities and hotspots: toward an anthropology of viral hemorrhagic fevers. *Med Anthropol Q* 28: 280–303.