

# Imagining viral hepatitis in Burkina Faso

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The announcement was so brutal, and the way that he told me about it, I was already digging my grave. (Student diagnosed with hepatitis B, Burkina Faso)

This student, recalling the moment he learned from a blood donation centre nurse that he was infected with hepatitis B virus (HBV), imagined his impending death. Hepatitis B, a viral disease that affects the liver, sometimes with fatal consequences, is endemic in Burkina Faso and West Africa. As with other people diagnosed with hepatitis B, the student momentarily interrupted his narrative about his diagnostic and therapeutic pathway to imagine a future consequence of his illness. Such fleeting, daydreamed moments of physical deterioration and death, and, for others, of abandonment and social isolation, guilt and occasionally complete healing, might easily pass unnoticed, but they are nevertheless fertile ground for exploration.

What follows is an excavation of these daydreams or ‘imaginings’ among some thirty people diagnosed with hepatitis B in Burkina Faso. We investigate what these imaginings do in grappling with the absences – of a certain future, of knowledge and of care – with which dreamers contend, the historical genealogies that give rise to these absences, and their longer-term consequences. In contrast to dreaming as a metamorphosis that ‘opens up the world’ for dreamers (Ingold 2011: 239), the imaginings of people living with hepatitis B offer an alternative interpretation: in the face of profound incertitude about the course that their infections will take and their ability to gain access to monitoring and long-term care, they seek to anchor themselves in precise social, material and bodily conditions.<sup>1</sup> Instead of ‘opening up’, these daydreams concretize and foreclose.

These ephemeral imaginings emerge from an ‘entanglement’ of the virus, epidemiological incertitude about its course, and absences within Burkina Faso’s health system and global health policies, which are themselves the

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<sup>1</sup>Our use of ‘incertitude’ draws from Stirling (2007), who defines the term as ‘incomplete knowledge’ taking multiple forms: uncertainty, ambiguity and ignorance. ‘Uncertainty’ refers to actors (including lay publics) knowing possible outcomes of an event, but not their probability; ‘ignorance’ is not knowing either possible or probable outcomes of an event; and ‘ambiguity’ is the framing of a problem in divergent ways and disputing its outcomes.

consequence of specific historical processes.<sup>2</sup> Hepatitis B infection, although not well known among the public or medical workers in Africa, affects between 6 and 20 per cent of sub-Saharan African populations (WHO 2015). Globally, viral hepatitis accounts for almost as many deaths as HIV, and more than tuberculosis or malaria (Chen *et al.* 2015; see also Cowie and MacLachlan 2013). More infectious than HIV, hepatitis B is transmitted through contact with bodily fluids, and in West Africa, where HBV is endemic, it most frequently occurs following birth, or in the first two years of life if a child is not vaccinated. Transmission early in life substantially increases the epidemiological risk of becoming a chronic carrier. Most people who are chronic carriers live full lives without suffering from the virus's damaging effects, or even any physical symptoms, and some can spontaneously rid themselves of the virus. Nonetheless, up to a third of people living with a chronic infection will develop cirrhosis or liver cancer (WHO 2015). Consequently, those living with chronic hepatitis B infection, as well as clinicians, virologists and epidemiologists, face great incertitude about how this infection might evolve. Their incertitude reminds us, then, that chronicity itself can be a highly fluid condition (Manderson and Morris-Smith 2011). Moreover, as a wealth of anthropological literature reveals more generally in Africa as elsewhere, these biologies are 'situated': who falls ill, who obtains diagnosis, monitoring and treatment, and who perishes from HBV is never exclusively a virological or epidemiological question. These concerns are bound up in political, economic, social and health conditions – under-resourced health infrastructures, health workers with limited understanding of hepatitis B, poor access to care and treatment (Lock and Nguyen 2010: 92; Lock and Kaufert 2001). These conditions in turn have been shaped by longer-term historical processes, underinvestment in African health systems, a global politics of hepatitis B control privileging vaccination over diagnosis and treatment, and a preoccupation with HIV's burden among lay people, health workers and authorities.

This article is part of a broader investigation into hepatitis B and its consequences in Burkina Faso and the Central African Republic. We conducted our research in Burkina Faso between 2012 and 2014 in the country's three largest cities: Ouagadougou (population 2.3 million), Bobo Dioulasso (537,000) and Banfora (93,000) (INSD 2013). These urban centres possessed at least limited screening and diagnostic capacities for HBV, permitting us to identify and interview people who had been diagnosed with the illness. Our research involved eighty-four in-depth individual interviews with older adolescents and adults diagnosed with chronic HBV, family members, medical personnel (gastroenterologists, general practitioners, nurses and a social worker), medical authorities, leaders of two advocacy associations of people with viral hepatitis, people undergoing viral hepatitis screening, and phytotherapists and healers. We held many informal discussions with the same informants and conducted participant observations of consultations and diagnostic announcements in two blood donation and transfusion centres (in Ouagadougou and Bobo Dioulasso), of a Ouagadougou hospital's gastroenterology department, at the 2013 World Hepatitis Day in Ouagadougou, and of healers' consultations in Ouagadougou and rural villages outside Banfora.

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<sup>2</sup>'Entanglement' has been a long-standing, fruitful theme within Margaret Lock's work, but for recent approaches, see Lock (2013), Lock and Nguyen (2010) and Nading (2014).

We begin by situating our reflections on ‘imaginings’ in recent contributions on daydreams and reverie, and their relations with incertitude. We then evaluate the recollections of diagnostic and therapeutic itineraries among three people living with HBV, their imaginings over alternative pathways and their bodily and social consequences. Our analysis turns to an examination of proximate absences that permit such imaginings and to a tracing of their longer-term historical genealogies. Finally, we examine the effects of these dreams and their consequences for the social and material lives that people with HBV lead.

### Imagining and incertitude

What we call ‘imagining’ takes its inspiration from recent work on reverie and daydreaming, although the work that imagining accomplishes is different. Nancy Rose Hunt (2008; 2014; 2016), drawing on Gaston Bachelard (1961), contends that reverie ‘expresses an aspiration ... opens the imagination’ to alternative futures (Hunt 2014: 118). Importantly, it occurs during a state of wakefulness, permitting the daydreamer to imagine consciously and to project a certain kind of future. In Hunt’s hands, reverie opens up a history of Equateur Province in the Belgian Congo, not only to reflect on trauma and sexual violence during the period of ‘red rubber’, but also to cast light on spaces of refuge and autonomy, on aspirations for a Congo without Belgians. John Borneman, drawing heavily on psychoanalysis, similarly uses reverie to show how Syrian men voice ‘gender, religious and economic anxieties’ and how they imagine futures unconstrained by the social rules under which they must live (2011: 240).

Like reverie or daydreaming, imagining also occurs in a state of wakefulness, but it is a much more restricted, condensed moment of fantasy and does not visualize a broader array of possible futures and pasts. Instead, as we will show here, people articulated alternative explanations, aspirations and fears about past and future consequences of their infections with hepatitis B as a way of anchoring their profoundly unknowable futures.<sup>3</sup> This profound unknowability raises, of course, an anthropological preoccupation with ‘not knowing’ (Last 1981; Littlewood 2007; Mair *et al.* 2012; Geissler 2013). Andy Stirling’s parsing of incertitude and its different forms (risk, ambiguity, uncertainty and ignorance) has been useful in delineating the possibilities, probabilities and ways of framing problems and categories as lay publics engage with scientific knowledge (Stirling 2007; Giles-Vernick *et al.* 2016). In Burkina Faso, imagining is a response to conditions of deep incertitude about how one’s infection will develop, and about whether and what kind of social and material consequences of diagnosis, treatment and healing exist. It deviates into alternative pasts and anchors unknowable futures in specific consequences, both aspirational and horrifying.

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<sup>3</sup>We do not use Charles Taylor’s ‘social imaginaries’, defined as the broadly shared ‘ways in which people imagine their social existence, how they fit together with others, how things go on between them and their fellows, the expectations that are normally met, and the deeper normative notions and images that underlie these expectations’ (Taylor 2002: 106). Our more restricted research does not justify making such sweeping claims for the people we interviewed.

### Three stories of incertitude and imagining

The following narratives reveal how imaginings are embedded in recollections of people with hepatitis B about their diagnostic and therapeutic itineraries. The first case is that of Mariam, a woman who suffered with debilitating symptoms for over a year and eventually sought herbal treatment from a phytotherapist. In the second case, Karim recounted his experiences with malaria-like symptoms for more than two years. He received a diagnosis of chronic hepatitis B and took an antiviral treatment but abandoned it because he lacked the means to pay for it. Finally, in the third case, Arlette described the struggles and reflections of a woman diagnosed with HBV following a blood donation. She never sought monitoring and treatment, but her sister, also chronically infected with hepatitis B, was receiving antiviral treatment for her condition. Although each of these people had a specific story to tell of diagnosis and life with hepatitis B, they shared important resemblances with other people living with HBV with whom we spoke, and thus, where relevant, we cite these other interviews.

These recalled diagnostic and therapeutic narratives all pivot around profound incertitude about the nature of hepatitis B, how it would evolve, and whether it would disappear altogether; about whether and what kinds of treatments were available; whether they were affordable and obtainable; and how other people understood the ailment and would interact with or abandon the afflicted person. Imagining played with temporalities (the imagined past and future trajectories and the consequences of infection in the face of incertitude), with reimagining social relations and material conditions of illness, and, at times, with aspirations that our informants suspected were not achievable.

#### *Mariam: abandonment, death and a complete cure*

Mariam,<sup>4</sup> a forty-one-year-old married woman living with her husband, co-wife and three of her five children in south-western Burkina Faso, struggled for over a year before receiving a diagnosis of hepatitis B (for other interviewees experiencing a similar struggle: Patient (P) 1; P3; P6; P8; P14; P19; P21; P31). Two years prior to our interview, she had fallen ill, initially from what she thought was *sumaya* (in the Djula language), a 'cold fever' that bears some resemblance to malaria (Giles-Vernick *et al.* 2011; Dacher 1990; Bonnet 1986). Her illness persisted despite her home treatments, so she consulted two healers in turn, both of whom insisted that she was the victim of sorcery, that she make sacrifices and that she drink and bathe in a herbal infusion. She suffered for many months from debilitating headaches and weight loss. Eventually, her mother's brother decided to take her to a local medical clinic for consultation and testing, where she received a diagnosis of hepatitis B and was encouraged to consult a local pharmacist, Dr D. This pharmacist's standardized herbal remedies for hepatitis B, malaria and other illnesses were widely distributed throughout the country.<sup>5</sup>

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<sup>4</sup>All names have been altered to protect informants' anonymity.

<sup>5</sup>In multiple interviews with Dr D, we found that he learned of these herbal treatments from local 'traditional' healers, but then repackaged them in infusion and capsule form. His patients come from throughout West Africa.

After taking the remedy (nine capsules daily) for a month, she said, 'I was standing up again. My body began to change, and little by little, regained my previous shape.' A year later, she had resumed her normal daily activities and no longer suffered with her previous symptoms.

In Mariam's recounting of her diagnostic itinerary and her reflections on her current state of health, we find two significant examples of incertitude that led her to imagine alternative explanations of her illness and the consequences of her treatment. First, recalling the very worst of her past suffering, Mariam made multiple references to HIV/AIDS (P6; P8; P14; Family member (F) 1; F3). As she inexplicably continued to lose weight before her diagnosis, she recalled, 'People who came to see me looked at me strangely. The rumours began to fly that it was AIDS. In truth, I wished for my own death at that moment.'

*Mariam:* People, they said everything about me!

*Interviewer:* About you, or about your illness? What were they saying?

*Mariam:* About me! It's the same thing, about my illness! People were thinking that I had AIDS. And because everybody knows it kills, they looked at me as if I were a cadaver. And when they think that you have AIDS, that means you aren't serious, that you sleep with a lot of men. And when it's like that, if you husband doesn't understand, he can chase you off!

Not knowing what was ailing her, Mariam herself wondered whether she was infected with HIV. She was convinced that her husband thought so. Even when the phytotherapist explained that she was infected with hepatitis B and not HIV, she was confused by his explanation, asking, 'What could be in the blood that is transmitted by blood and by sexual relations if it isn't AIDS?' Her husband subsequently underwent screening for HBV but tested negative for this viral infection. She concluded: 'I [finally] understood that it wasn't AIDS.'

For Mariam, her neighbours and her husband, HIV thus worked as an alternative framing of her illness. Although hepatitis B and HIV are entirely different viruses acting on the human body differently, resemblances in symptoms (weight loss, nausea) and medical explanations of certain transmission modes (blood and sexual contact) sustained this alternative framing. At the same time, there is much in Mariam's ambiguity that is imagined. Shifting from what 'people' knew about AIDS and how they observed her 'as if I were a cadaver', she then imagined that an HIV diagnosis would brand a woman as not 'serious', as having many sexual partners. Recalling this period of deep incertitude and suspicion concerning her affliction, Mariam thus re-envisioned her past, anchoring it in concrete, dire consequences: death and social abandonment.

The second realm of ambiguity in her recollection centres on the significance of 'healing'. A year after taking Dr D's herbal therapies, she described her 'healing' in this way:

Look at me yourself: do I look like a sick person? Now, I can do everything that I want! ... You would never know by looking at me that I had anything ... When I was sick, [my husband] didn't touch me. He had such pity for me. [*She laughs.*] But he began to touch me not very long ago. It was when he saw really, that everything was fine.

For Mariam, she had achieved health because she looked healthy, had no physical symptoms of illness, could do ‘anything’ she wanted and had resumed sexual relations with her husband. She attributed this healing to a lengthy process of diagnosis that resulted in the good fortune of finding a ‘good medicine’, one that made her feel healthy. Imagining an alternative outcome, she then reflected that having a hepatitis B infection could have important consequences:

if you aren’t paying attention. Let’s say you don’t have the good fortune to find a good medicine. First, you’re going to die pretty quickly. Me, if it hadn’t been for my uncle who had the idea of this medicine, I’d be taking false medicines and maybe one day I wouldn’t be around anymore!

Again, Mariam reimagined an alternative trajectory of her past diagnostic and therapeutic itinerary, anchoring it in her death. Such imaginings, shared by other informants, focused on the fortuitous intervention of a family member who steered her to the right therapy (P8; P17; P11; P13; P14; P18; P21).

This fleeting moment of imagining an alternative path is linked to Mariam’s fundamental uncertainty about what would happen to her infection, and about whether she was truly healed. ‘Eh!’ she subsequently worried:

The illness has not really left my body. Only the medicine that I take works so that I can live normally! This is what Dr D says. So, perhaps if I stop taking the medicine, I will fall ill again. I won’t stop taking it until the doctor tells me to. But he says that after a certain period of time, there are those who are completely cured, but you have to take the treatment for a very long time. It depends on people. The bodies of people are not the same. Some have blood that is stronger than others, so it depends.

Here, then, Mariam acknowledged that she was not completely healed because the virus remained in her body. This incomplete knowledge of what would happen to her offered a space for her to express an aspiration of being ‘completely cured’ – cleared altogether of her illness. In so doing, she evoked something akin to Lock’s ‘local’ or ‘situated’ biologies. She observed that blood – at once a biological fluid, a substance shared by members of a lineage, a possible reference to the earliest human life form in utero, a vehicle for ‘dirt’ to travel throughout the body and to lodge in specific organs and cause illness – could explain why some people heal fully and others do not. For Mariam, different ‘blood’ accounted for divergent consequences of infection with hepatitis B. Her evocation of blood and viral clearance thus offered a space to express her aspiration of ‘complete cure’.

### ***Karim: ‘This isn’t my body’***

Karim, a forty-seven-year-old married man living with his wife and four children in Ouagadougou, sought diagnosis and treatment for his ailment for more than two years before receiving a diagnosis of hepatitis B. Four years before we interviewed him, he was working as a chauffeur and began to suffer from unexplained fevers. Like Mariam and several other informants, Karim initially thought his intermittent fevers were malaria, brought on by fatigue from constant travel. He insisted:

Every week, I fell strangely ill, like it was malaria ... Me, I thought that maybe it was work, that it was fatigue. That’s what I was thinking. I thought it was fatigue because

I travelled too much. I thought that it was driving that was making me tired ... I even thought – I did all of the tests, the test for AIDS, even that I did. But there was nothing.

For two years, he consulted medical personnel at his local healthcare clinic (Centre de Santé et de Promotion Sociale or CSPS), received antimalarial and anti-febrile medications, but to no avail. His ‘malaria’ persisted. He gave up working as a driver because of his illness.

Eventually, Karim contacted Madame Yara, an acquaintance and technician at the Hôpital Saint-Camille in Ouagadougou. She was also the president of SOS Hépatites, a Ouagadougou-based association of people diagnosed with viral hepatitis but also affiliated to the international NGO SOS Hepatitis. He lamented to her, ‘This malaria, it’s going to kill me.’ She drew his blood for testing, and, later that day, called to give him his diagnosis: he was infected with hepatitis B, a ‘liver problem’. With her financial assistance, Karim consulted one of Burkina Faso’s few gastroenterologists and underwent numerous tests, including a liver sonogram to assess damage that chronic carriage of the virus had inflicted on his liver. The gastroenterologist concluded that Karim required treatment, putting him on an antiviral medication, lamivudine, that he was to take daily for life. Karim took the medication for some time. Asked whether the medicine ‘healed’ him when he took it, he responded: ‘It’s calming; I can say that it calms my illness, because if I take it today, I’m fine, tomorrow I’ll be fine. But one week later [if I don’t continue taking the medicine], the illness will return.’

Karim’s assessment of the effects of lamivudine may reflect how he took the medicine, and particularly his interruption of treatment after a year. Karim emphasized that the medication ‘calmed’ his symptoms. He distinguished ‘calming’ from ‘healing’, suggesting that he spaced his treatment to make his medical stocks last longer, but that his symptoms returned after the palliative effects of the medication wore off. It was unclear from his discussion whether he had ever taken lamivudine consistently, or whether his understanding of ‘calming’ resulted from his later experiences of treatment. His reasons for interrupting treatment, he said, were financial: after abandoning his work as a driver, he sold sand to make a living. But he could not earn sufficient sums to pay for his children’s needs and his treatment. According to Karim’s wife, these conflicting claims on their meagre resources caused familial strife.

For Karim, one recurrent uncertainty centred on how his illness would progress, particularly because he no longer received treatment. He knew what the possible outcomes were: twice he mentioned the death of his father’s younger brother from HBV, but he frequently discussed the experience of a friend, also afflicted with HBV, who had cleared the virus from his body. ‘Well, thank God, he has financial means,’ Karim observed.

*Karim:* And for him, it’s finished.

*Interviewer:* Finished, finished?

*Karim:* Completely finished ... Me, I don’t know, in any case, me, I didn’t ask. Hmm, I didn’t ask. But it was the day that I did this [I found out about my illness] and I went to explain to him. He said, it was the same for him as well, it was the same. But he stopped drinking and took medicine, but they, they have money to treat it. You have

to have good medicines. We, we're poor. [*Laughs.*] But for him, no, it's finished and he is healthy.

We cannot know what happened to this friend. Was he one of the rare people who received an interferon treatment (at the time of writing, largely ineffective against the viral genotype circulating in Africa) and was cured? Did he spontaneously clear the virus from his body? In his uncertainty about the consequences of his own infection, Karim nevertheless believed that his friend had been fully cured. He clearly aspired to a full cure, but, laughing, he contrasted his poverty to his friend's financial situation, suggesting that it stymied his quest for 'good medicines' and a complete cure. Significantly, his reflections on uncertainty and aspirations for a complete cure were followed by his lapse into a moment of nostalgia. Wistfully recounting his bodily health before falling ill, he mourned, 'This isn't my body. I was in shape ... I used to weigh 91 kilos, but now I'm 72 kilos.'

Karim's uncertainty about what would happen to his infection thus provoked a brief imagining of multiple, specific future and past trajectories. He aspired for his illness to be 'finished' and simultaneously expressed dejection that his poverty prevented this and that his once robust body had been transformed into something that was not his own.

### *Arlette: a 'patient-in-waiting'*

In contrast to Mariam and Karim, Arlette, a forty-nine-year-old unmarried teacher with no children, was not ill prior to her diagnosis. A Ouagadougou resident, she received her diagnosis in 2003 following her first blood donation (P1; P4; P5; P7; P9; P10; P11; P12; P13; P15; P16; P17; P20; P22; P24; P26; P27). The attending social worker at the blood bank informed Arlette that she was a 'healthy carrier', someone who 'had the virus but lived with it'.<sup>6</sup> Her donated pouch of blood would be discarded to avoid infecting another patient. 'And so,' she concluded, 'I was eliminated from [making] this humanitarian gesture.' At the time of the screening announcement, she confessed complete ignorance of HBV. 'I wasn't afraid of this hepatitis,' she confided, 'because I didn't even know what it was. It wasn't worth getting crazy over nothing.' She ended with a laugh. She subsequently met Mme Yara, the SOS Hépatites president. Arlette joined the association and learned considerably more about HBV, which she came to see as a 'very, very serious disease'. She said she had no symptoms, was not monitored, and received no treatment. Her younger sister, also infected with HBV, had consulted a gastroenterologist and had just started taking an antiviral treatment.

Arlette's fundamental incertitude centred on whether she was sick or healthy and on what being a 'healthy carrier' meant for her present and future social relations and health. Her liminal state generated myriad questions for Arlette about the nature of HBV itself, the treatment she should take (or not take), and the danger she posed to people living with her, and expressed itself in her ambiguity and contradictory claims, providing an opportunity for her to imagine a grim future for herself.

<sup>6</sup>Our participant observations revealed that nurses and social workers making these announcements frequently, but not always, used the term 'healthy carrier' to explain the screening results to patients.



Concerning the nature of hepatitis B, Arlette suggested that her initial dearth of knowledge about the illness gave way to a new understanding of its dangers. Indeed, throughout her interview, Arlette slipped easily into framing hepatitis B in terms of HIV/AIDS, since hepatitis had ‘almost the same modes of transmission’ as HIV: blood contact, but also through sexual relations, from mothers to babies during the birthing process, and through contact with the saliva of an infected person (others thought similarly: P1; P2; P7; P9; P13; P15; P17; P18; P19; P22; P26; P25).<sup>7</sup> She initially asserted that she did not fear her diagnosis, but she subsequently contradicted herself, admitting that she daydreamed of a physical degeneration and death resembling those of someone with AIDS.

*Interviewer:* When you were told that you had hepatitis, what did you think about at that moment?

*Arlette:* I thought of suffering, of decay, of a real, bodily physical degradation. That, that could be due to – I was told afterwards that it is like AIDS. I’ve seen people who were sick from AIDS, I’ve seen people who were sick from AIDS, and I practically saw them in my arms, one died in my arms.

HIV thus framed Arlette’s understanding of hepatitis B, perhaps because she received her screening announcement where blood donation and pathogen screening, most notably for HIV, occurred.

Arlette simultaneously struggled to make sense of HBV’s differences from HIV and particularly what it meant to be a ‘healthy carrier’. She initially claimed that she did not know whether she posed a danger of infecting other people with whom she lived.

I had to do the test that showed whether you were a healthy carrier or not. I don’t know the technical terms, but it was found that my body had developed antibodies and my antibodies were of a sufficient level to control the virus in my body. Now I don’t know if I can contaminate – on that, I don’t have any information. I think somebody told me, but I’m not very sure, but I don’t think I’m a danger.

Yet moments later in the interview, prodded by the interviewer’s question about her fears, Arlette expressed her fear that she would ‘contaminate’ someone, and imagined the consequences of this transmission:

Well, my fear is that I would contaminate someone else. Yes, that, that makes me more fearful than for myself. Because it’s a really heavy burden, knowing that you’ve made someone else sick. If you yourself are sick, that’s fine, you didn’t seek it out, you didn’t pick it out, you didn’t buy it. Yes, in that case, you can accept it ... But another

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<sup>7</sup>HBV transmission in sub-Saharan Africa complicates some of Arlette’s claims. First, sexual transmission of HBV is possible, but in sub-Saharan Africa most people are exposed in the first years of life if they are unvaccinated, or, less frequently, in the birth process or just after birth (Shimakawa *et al.* 2015b). Most adolescents and adults engaging in sexual relations have therefore already been exposed to HBV. The virus has been found in minute quantities in saliva. Hepatologists and epidemiologists consider transmission risk through saliva to be minimal, but not zero (Shepard *et al.* 2006).

person, if this person doesn't protect herself and goes to other people, and so on, that's frightening for me.

Displacing her imagined experience of infecting another person to 'you', Arlette thus imagined a morally burdensome scenario in which she catalysed other infections. Indeed, she recounted how she had given birth to a stillborn child ten years earlier and, since then, had tried to find out whether the infant's death was due to her own HBV infection. 'I have so many questions without answers,' she lamented.

Living as a 'healthy carrier' – evoking Stefan Timmermans' and Mara Buchbinder's 'patient-in-waiting' – Arlette existed in limbo, neither healthy nor sick (Timmermans and Buchbinder 2013). A 'patient-in-waiting' lives in a liminal state, in which neither the patient nor his or her family can assume that he or she is healthy, nor can they presume that the patient is ill; the menace of illness hangs in the near or extended future (*ibid.*: 96). Patients-in-waiting 'experience the anticipation of a disease that they may never acquire', and this frames their 'medical encounters ... [and] life strategies' (*ibid.*: 96). We find this 'anticipation of a disease' in Arlette's efforts to grapple with the great incertitude about the nature of her infection and its evolution and in her anchoring her imaginings in dire consequences – her own grim death and the infection of her child.

### Proximate absences and their historical genealogies

Hepatitis imaginings, then, anchored alternative pasts and unknown futures in specific outcomes, some grim and others aspirational. These imagined pasts and future consequences of Mariam, Karim, Arlette and the other people interviewed were effectively made possible by what we call 'proximate absences', defined as certain biological and epidemiological, infrastructural and political absences, privations or deficiencies. We treat these proximate absences in turn, but recognize them as profoundly entangled.

First, as with many cases of chronic hepatitis B infection, the three stories are marked by an invisibility or non-specificity of symptoms, a frequent feature of the viral infection itself. Very young, unvaccinated children tend to have no symptoms at all when first infected, and chronic carriers often do not manifest symptoms for several decades, as in Arlette's case. Moreover, once a chronic infection provokes symptoms, both sufferers and medical workers can offer alternative explanations for them. Karim thus explained his symptoms as 'malaria'; Mariam initially treated herself for 'cold fevers' but was subsequently diagnosed by two healers as the victim of sorcery. As her symptoms persisted, both she and her neighbours suspected HIV. Mariam, her neighbours, Arlette and many other informants drew on an alternative framing of HBV, which they characterized as 'just like' HIV in its transmission, symptomology and consequences, if left untreated. Clearly, an absence of specific bodily symptoms made these imagined framings of illness possible, and of the physical deterioration and social exclusion that accompanied it.

An epidemiological feature of hepatitis B, the absence of prognostic certainty, also gave rise to imagining. Epidemiologists identify and evaluate risk factors to predict what will happen to people infected with HBV. Many chronic carriers live with the inactive virus in their bodies without health consequences, and

thus require no treatment. But for 20 to 30 per cent of these chronic carriers, the virus provokes an inflammatory response in the liver, a response that may go entirely unnoticed by carriers themselves because they have no symptoms (Shepard *et al.* 2006). Decades later, this inflammatory response can result in cirrhosis and/or liver cancer. Those infected in early childhood face a much higher risk of developing liver disease later (Shimakawa *et al.* 2015a; 2013; Edmunds *et al.* 1996). Yet despite epidemiological predictions, no one can predict how an individual's infection will develop. Arlette is thus truly a 'patient-in-waiting', unable to know whether her chronic infection will clear up, remain inactive or develop into serious liver disease. This incertitude gave way to imaginings about the longer-term consequence of her infection, particularly the physical debility that could accompany the disease.

Another proximate absence, broadly infrastructural, gave rise to these imaginings. Although some 12 per cent of Burkina Faso's population is chronically infected with hepatitis B (Schweitzer *et al.* 2015), the country possesses neither the human nor infrastructural resources to contend with this health problem. In a country with very few qualified gastroenterologists,<sup>8</sup> most health personnel whom we interviewed admitted to having a very poor understanding of HBV, its transmission and long-term care. Moreover, our analysis of blood centre screening announcements of HBV infection in Bobo-Dioulasso and Ouagadougou revealed that blood donors frequently received insufficient or erroneous information about hepatitis and its treatment (Giles-Vernick *et al.* 2016). The student quoted at the beginning of this article was erroneously told by the nurse announcing his screening result that 'modern medicine' offered no treatments for HBV. Small wonder, then, that he imagined himself digging his own grave.

Much of Burkina Faso suffers from a lack of screening, diagnosis and monitoring capacity, and its citizens have very poor access to qualified care. Mariam's case is instructive here. Diagnosed at a medical clinic, she nonetheless sought treatment from a phytotherapist, Dr D. She did not explain her decision to consult a phytotherapist, only that her uncle directed her to him. This decision is likely due to the wealth of phytotherapeutic remedies for hepatitis B in Burkina Faso, combined with a relative absence of biomedical offerings. The West African International Fair of Natural Remedies (SIRENA), held annually in Ouagadougou, offered myriad remedies for hepatitis B, and many promised a 'complete cure' – hence Mariam's envisioning of a projected future of full cure, as well as an alternative past of not finding a 'good medicine'. Other informants also sought out these remedies as well (P3; P17; P18; P19; P25; P29; P30).

At the same time, biomedical options were severely limited for Mariam, as well as for Burkinabes living outside Ouagadougou or Bobo-Dioulasso.<sup>9</sup> Mariam had

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<sup>8</sup>SOS Hépatites indicated that there were thirty gastroenterologists in the entire country in 2015 (2 April 2015).

<sup>9</sup>On inequities in Burkina Faso's healthcare, see Ridde (2008). Burkina Faso's healthcare system is organized around primary care, regional and national structures. The CSPSs and small clinics, staffed by a senior nurse, an assistant nurse and a midwife, offer primary care and cover an average of 10 square kilometres and between three and twelve villages. Most often, rural people initially consult personnel at the CSPSs, which have their own pharmacies selling generic drugs. More complex medical cases are referred to a *centre médical* or *centre médical*

access only to an initial screening exam in Banfora. Of our three research sites, the Cascades region (Banfora) suffers the greatest dearth of medical structures, personnel and resources, with only one regional hospital, one medical clinic providing simple surgeries, and sixty CSPSs (INSD 2013). Had she sought diagnosis and long-term monitoring (costing at least €70 per year), she would have had to travel to Bobo-Dioulasso to consult a gastroenterologist and to be tested. Even if patients were fortunate enough to find physicians who could follow and treat them, many with whom we spoke could not afford their services, monitoring or medications. The debilitating effects of Karim's illness forced him to quit a more lucrative profession, and eventually he stopped his treatment because he could no longer pay for it. The scarcity of personnel and infrastructural resources thus seems to have fed Mariam's and Karim's imaginings of a complete cure, as well as nightmares of physical debility.

Indeed, a cure for HBV remains elusive. Interferon treatments are not especially effective for the HBV genotype circulating in Africa, so the best available options for those needing treatment are antiviral drugs, tenofovir and lamivudine, taken for life to prevent liver damage. Although these drugs are free of charge for those diagnosed with HIV because of its inclusion in the Global Fund, in 2015 HBV patients paid about €4.50 per month, a sum largely unaffordable by Burkina Faso's poor. These antivirals do not promise 'complete cure' but rather inhibit liver inflammation and prevent cirrhosis and liver cancer. The existence, but lack of wide availability, of these antiviral treatments was surely an absence that sustained Karim's claims that his body was not his own, his imaginings of consistent treatment, and his longing for full cure.

These proximate biological, epidemiological and infrastructural absences are themselves the consequences of historical processes – of underinvestment in health training and capacity, of an absence in national and global political commitments to investing in health personnel and structures and to making antiviral treatment available for people living with chronic infection, and of HIV's place in African global health.

Burkina Faso's health system and personnel resemble those of many other sub-Saharan African countries: it suffers from the violence of scarcity. At the same time, Burkina Faso is one of the poorest countries on the planet, and the dearth that characterizes its health system has a lengthy history, beginning under French colonial rule (Bado 1996). French colonizers sorely neglected training health personnel and developing infrastructure, particularly outside Ouagadougou and Bobo-Dioulasso. Although the Upper Volta State, subsequently renamed Burkina Faso, sought to compensate for this earlier history of neglect, particularly during the Sankara era, substantial underinvestment in training, in the hiring of competent personnel and in infrastructure and health resources has largely continued since 1960 (Samuelson 2001).

This dearth is also a consequence of the contemporary history of national and global health politics around hepatitis B, which have channelled resources into

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*avec antenne chirurgical* (a medical structure conducting basic surgery). The Centre Hospitalier Régional receives more complex cases referred from the district health centres. Burkina Faso has three national teaching hospitals, accepting referrals from regional hospitals and delivering specialized care.

prevention through routine childhood vaccination but have simultaneously avoided committing resources to making monitoring and treatment accessible to people living with the illness (Lemoine *et al.* 2013). Burkina Faso, like most sub-Saharan African countries, has no programme to monitor and treat people with HBV. Although the hepatitis B vaccination has existed for decades, many sub-Saharan African countries did not integrate it into their Expanded Programmes on Immunization until the 2000s, with the crucial assistance of the Global Alliance for Vaccines and Immunisation (GAVI) (Brugha *et al.* 2002). Burkina Faso did so in 2006, delivering the HBV vaccine as part of a single ‘penta-valent’ vaccine (which also protects against *Haemophilus influenzae* type b, diphtheria, tetanus and pertussis) for infants at eight, twelve and sixteen weeks of age. The result is that Burkinabes over thirteen years old (over half of the total population) have largely gone unvaccinated, although 90 per cent of this same population has already been exposed to HBV. Infant vaccination, although important, fails to tackle the problems of monitoring and treatment affordability and accessibility, beleaguered and poorly trained health workers, and insufficient health infrastructures and resources. Hardly surprising, then, that those living with HBV aspire to obtain treatment, or even a complete cure, and envision their future isolation and suffering when they are left to their own devices and resources, as Mariam, Karim and Arlette were acutely aware.<sup>10</sup> The absence of a national and global political commitment to ensure treatment fed both dreams of this possibility and projected nightmares of falling ill and finding treatment inaccessible.

A final historical genealogy of the absences that underpin hepatitis dreams centres on HIV. HIV’s histories of emergence, illness, testing, diagnosis and battles for treatment in Africa have had a huge effect on imaginings of HBV in Burkina Faso. Tracing the history of HIV in Africa is beyond the scope of this article (see, for instance, Eboko *et al.* 2011; Nguyen 2010) but HIV’s spectre looms large in many aspects of HBV, from blood donation centres, where HBV is routinely screened, to its modes of transmission, certain symptoms and the anti-viral treatments used to manage both viral infections, and even global publicity about HBV. Publicity for a past World Hepatitis Day noted: ‘Viral hepatitis kills 1.5 million people worldwide each year. That’s as many people as HIV/AIDS.’

The spectre of HIV can be understood in terms of ‘material proximities’ – Joost Fontein’s notion that exhorts us to attend to ‘an acute sensitivity to the proximities, coexistences, and continuities that derive from people’s shared material and historical engagements’ (Fontein 2011: 723). Hannah Brown and Ann Kelly have productively extended this notion to explore viral haemorrhagic outbreaks, arguing for multi-spatial, multi-scalar, multi-temporal explorations of how viruses, people, institutions and objects coexist, over time becoming entangled in shared landscapes to emerge as epidemics (Brown and Kelly 2014). HBV and HIV reflect important ‘material proximities’ in screening practices and sites, treatments, bodily fluids and modes of transmission, as well as in models of political

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<sup>10</sup>At the time of writing, in sub-Saharan Africa, only Senegal had a national programme to control viral hepatitis, yet, thus far, even this does not assure the follow-up and treatment of those with chronic HBV infections. In Africa, only Egypt has a functioning national programme to ensure the diagnosis and treatment of viral hepatitis.

mobilization. These proximities enabled Mariam and her neighbours to imagine her social exclusion and abandonment; they fed Arlette's dream of her future physical deterioration, possibly avoiding having children for fear of transmitting her viral hepatitis. They permitted the student at the beginning of this article to project his own death. And they offered members of SOS Hépatites, an association from which we recruited some of our informants, a historical model with which to dream of and to fight for access to treatment.

This history, the absences of knowledge, health resources and political commitment that it may underpin, and the imaginings that it sustains suggest that there may be a different story to tell about HIV exceptionalism and the debates about whether or not it is a chronic disease 'like any other' (Moyer and Hardon 2014; Setbon 2000; cf. Dionne *et al.* 2013). The stories of Mariam, Karim and Arlette reveal how HIV has powerfully reframed conceptions, experiences, incertitude and aspirations to treatment and care around chronic hepatitis B.

### Conclusion: what imaginings do

We have explored how people living with hepatitis B in Burkina Faso diverged from describing their diagnostic and therapeutic itineraries to imagine the past and future pathways that their illness, social relations and material conditions may follow. Several proximate absences gave rise to these dreams, from the virus's biological and epidemiological features to the dearth of healthcare training, resources, infrastructure and treatments in Burkina Faso. These absences, in turn, were generated by their own historical processes, including a long history of underinvestment in Burkina Faso's healthcare structures and personnel; a more recent history of HBV control in Africa that focuses exclusively on infant vaccination but has left the legions of sick and chronic carriers without access to testing, monitoring or effective medicines; and the 'material proximities' of hepatitis B and HIV that have facilitated the extraordinary imprinting of HIV on imaginings of HBV.

We conclude here with some reflections on why these momentary imaginings are worth exploring, what they do for wakeful dreamers, and what they might accomplish politically. Confronting profound incertitude about the past and future courses of their infections, Mariam, Karim and Arlette imagined in fleeting moments alternatives to their bodily and social conditions. As we have sought to show, they did so not to open up myriad possibilities, but rather to anchor their pasts and futures in specific, defined outcomes.

For some people coping with long-term infections, imagining alternative pasts raised comparisons with and offered comfort about their present conditions. Mariam, for instance, reimagining a different set of decisions and consequences of death and social isolation in the past, comforted herself that she had found a 'good' medicine rather than something that failed to alleviate her symptoms or re-establish her health. In this way, her diagnosis with HBV and treatment by a phytotherapist allowed her to avoid the specific horrors of an HIV diagnosis, her neighbours' recriminations, and abandonment by her husband.

Dreams projected into the future could be double-edged, for they concretized both aspirations and potential nightmares. Karim's envy of his well-heeled, fully cured friend and his own hopes for a complete healing expressed a reassuring aspiration – an alternative, perhaps, to his present frustrations at not being able

to afford treatment and his incertitude and fears about his physical degradation. In a sense, then, Karim's dream was one without material consequences, other than his anger at not having wealth to alter his current situation. Arlette, on the other hand, vividly envisioned her own physical debility, projecting a nightmare of her deterioration and death. Overdetermined by her experiences of HIV, this imagining may have helped her prepare herself for future sickness, or may have simply expressed a fear of what might happen.

Imagining may also have provided grounds for configuring social relations. Arlette expressed uncertainty about whether she could transmit her infection to another person and wondered if her lost pregnancy was due to hepatitis. We did not ask her whether she chose not to have children because of her infection, although childlessness is unusual for forty-nine-year-old Burkinabe women. Nonetheless, we wonder whether she made this choice so as not to pose a risk to another person. Other young HBV 'patients-in-waiting' whom we interviewed insisted that they remained unmarried and without children because of their incertitude over their infections; others deferred their professional and educational aspirations.

Finally, we contend that these fleeting wakeful dreams not only help our informants to anchor specific imagined consequences in the face of profound incertitude. Their imaginings, and those of others living with hepatitis B, may help rework political relations around the illness's screening, diagnosis and treatment. As a way of coping with the incertitude of a chronic hepatitis B infection and imagining its nightmarish future trajectories, several informants, including Arlette and Karim, joined SOS Hépatites, the Ouagadougou association organized by and for people diagnosed with hepatitis and supported by the international NGO SOS Hepatitis. They joined the association to better understand the complexities of their illness, but also to mobilize politically to address the problems of the testing, monitoring and treatment needs of people in Burkina Faso with viral hepatitis. This effort has made slow but marked progress in the last few years. Collaborative efforts between the association members, the Ministry of Health and Burkinabe gastroenterologists have resulted in a new national plan for the screening, diagnosis and treatment of viral hepatitis. In addition, Nicolas Meda, a prominent medical epidemiologist specializing in viral hepatitis and HIV, was appointed Minister of Health in 2017. Perhaps, then, hepatitis nightmares can galvanize political action.

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### Abstract

This article explores ‘imaginings’ around hepatitis B in Burkina Faso and their historical genealogies. Hepatitis B is a viral infection afflicting the liver, but asymptomatic carriers may fall ill decades after exposure to the virus. Drawing from ethnographic interviews, we analyse how people living with hepatitis B in Burkina Faso grapple with uncertainty about the course of their infections, the possibilities for healing and their illness’s influence on social relations by ‘imagining’: that is, diverging momentarily from narratives about their diagnostic and therapeutic pathways to imagine alternative pasts and future consequences of this illness. We investigate how those living with hepatitis B use these imaginings to grapple with absences – of a certain future, of knowledge and of care – the historical genealogies that give rise to these absences, and their longer-term consequences. These ephemeral imaginings emerge from an ‘entanglement’ of the virus, epidemiological uncertainty about its course and absences within Burkina Faso’s health system and global health policies, which are themselves the consequence of specific historical processes.

### Résumé

Cet article explore les « imaginaires » de l’hépatite B au Burkina Faso et leurs généalogies. L’hépatite B (VHB) est une infection virale touchant le foie, dont les porteurs chroniques peuvent longtemps demeurer asymptomatiques et tomber malade plusieurs décennies après avoir contacté le virus. À partir des entretiens et d’observations ethnographiques, nous analysons comment les patients font face aux incertitudes liées à l’évolution de la maladie, aux perspectives de guérison et à l’influence de l’infection sur les relations sociales. Se distanciant des récits de leurs itinéraires diagnostiques et thérapeutiques, ils imaginent d’autres passés et les conséquences futurs de cette maladie. Nous étudions comment ces personnes vivant avec l’hépatite B utilisent ces rêves pour gérer certaines absences d’un avenir, de savoirs, de soins, des généalogies historiques qui ont produit ces absences, et leurs conséquences au long-terme. Ces rêves éphémères sont produits par l’enracinement du virus, de l’incertitude épidémiologique, ainsi que des absences au sein du système de santé burkinabé et des politiques de santé globale, qui sont elles-mêmes le résultat des processus historiques spécifiques.