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# BMJ Open Screening, diagnosis and care cascade for viral hepatitis B and C in Yaoundé, Cameroon: a qualitative study of patients and health providers coping with uncertainty and unbearable costs

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## ABSTRACT

**Objectives** To document patients' and healthcare professionals' (HCP) experiences with hepatitis B virus (HBV) and hepatitis C virus (HCV) diagnosis and care, as well as consequences of these infections on patients' life trajectories in Cameroon, an endemic country in sub-Saharan Africa.

**Design** Qualitative sociological study combining in-depth interviews and observations of medical consultations. Interviews and observations transcripts were thematically analysed according to the following themes: circumstances and perceptions surrounding hepatitis screening, counselling and disclosure, information provided by HCP on hepatitis prevention and treatment, experience of access to care and treatment, social/economic trajectories after diagnosis.

**Setting** HIV and gastroenterology/medical services in two reference public hospitals in Yaoundé (Cameroon).

**Participants** 12 patients affected by HBV and/or HCV (co-infected or not with HIV), 14 HCP, 14 state and international stakeholders.

**Findings** Many patients are screened for HBV and HCV at a time of great emotional and economic vulnerability. The information and counselling delivered after diagnosis is limited and patients report feeling alone, distressed and unprepared to cope with their infection. After screening positive, patients struggle with out-of-pocket expenditures related to the large number of tests prescribed by physicians to assess disease stage and to decide whether treatment is needed. These costs are so exorbitant that many decide against clinical and biological follow-up. For those who do pay, the consequences on their social and economic life trajectories are catastrophic.

**Conclusion** Large out-of-pocket expenditures related to biological follow-up and treatment pose a real challenge to receiving appropriate care. Free or reasonably priced access to hepatitis B and C treatments can only be effective and efficient at reducing the hepatitis disease burden if the screening algorithm and the whole pretherapeutic assessment package are simplified, standardised and subsidised by comprehensive national policies orientated towards universal healthcare.

## Strengths and limitations of this study

- Challenges surrounding screening, diagnosis and care for viral hepatitis B and C in Cameroon were investigated comprehensively in terms of state and international stakeholders, healthcare professionals and patients.
- Our qualitative sociological study combined in-depth individual interviews with observations in gastroenterology wards in two of the study sites where healthcare professionals and patients were selected for participation.
- The qualitative design of the study is especially suitable to highlight how the complexity of the diagnostic and the high-related costs (i) prevent most patients from accessing appropriate care and treatment, (ii) detrimentally modify their social and economic life trajectories over the long term.
- This study was only conducted in Yaoundé and thus does not reflect what happens elsewhere in Cameroon, especially in rural areas and in other sub-Saharan countries.
- Although this study was conducted before the arrival of direct-acting antivirals in Yaoundé, the challenges related to access to pretherapeutic tests and to treatment are still relevant today.

## INTRODUCTION

According to the 2017 WHO Global hepatitis report,<sup>1</sup> 257 million people are chronically affected by hepatitis B virus (HBV) and 71 million by hepatitis C virus (HCV) worldwide. Sub-Saharan Africa is one of the hotspots of these two epidemics. HBV infection is widespread in the continent, affecting >8% of the population in West and Central Africa, reaching 15% in some areas.<sup>2</sup> HCV infection is less evenly distributed with prevalences ranging from 1% in Senegal to 6.1% in Burkina Faso.<sup>3</sup>

HBV and HCV are bloodborne infections but their main routes of transmission in sub-Saharan Africa differ.<sup>4</sup> HBV is mainly transmitted at birth from mother to child (vertical transmission), during childhood through contact with infected blood (horizontal transmission) or through sexually (exchange of body fluids) or unsafe medical practices. HCV is mainly contracted parenterally through blood transfusion, unsafe medical practices and drug injection.<sup>5</sup> HBV and HCV disease progression leads to liver fibrosis, cirrhosis and hepatocellular carcinoma.<sup>6</sup> Antiviral treatments for HBV (eg, tenofovir) and direct-acting antivirals (DAA) for HCV can control viral replication, prevent disease-associated complications and even cure HCV.<sup>1</sup> Antiviral treatment for pregnant women living with chronic HBV infection is also required to prevent vertical transmission.

Viral hepatitis is a silent killer, long neglected in sub-Saharan Africa.<sup>4</sup> Most countries in the region lack national hepatitis prevention and treatment programmes. Vaccination against HBV is included in immunisation programmes but coverage is poor.<sup>1</sup> Immunisation at birth, which is now recommended to reduce vertical transmission, has only been adopted in a few countries.<sup>7</sup> Screening is suboptimal and late diagnosis (ie, when symptoms appear) is extremely frequent.<sup>4</sup> Moreover, the availability of effective antiviral treatments for HBV and DAA is very limited in most African health systems.

There is however a growing awareness about the global burden of viral hepatitis and its impact on communities' welfare. After the first resolution adopted in 2010 by the World Health Assembly which called for interventions for both prevention and control of viral hepatitis, WHO provided international guidelines for viral hepatitis screening and drew attention to this 'urgent public health matter'.<sup>1,8</sup> In addition, following the Dakar Call in July 2011,<sup>9</sup> healthcare professionals (HCP) in Africa advocated for mobilisation to fight against viral hepatitis in the continent, and collaborations involving health professionals and societies of gastroenterologists continue to grow today.

Despite the complex challenges to sub-Saharan HCP, patients and health systems mentioned above, most of these challenges remain dramatically understudied. Comprehensive assessments of the circumstances and experiences of patients and HCP in terms of diagnosis, counselling and care for both diseases are sparse,<sup>10–12</sup> especially in countries with poor access to related medical care. In this study, we aimed to document circumstances and perceptions surrounding HBV and HCV screening and counselling, and experiences with regard to access to care and treatment, and the impact these infections have on social and economic trajectories of patients in Yaoundé, the capital city of Cameroon.

## METHODS

### Context

Cameroon is a lower middle-income country of Central Africa with a yearly gross domestic product (GDP) of

US\$1354 per capita in 2015 and a literacy rate of 80% in young adults (15–24 years).<sup>13</sup> However, human development indicators remain low: with a human development index of 0.55 in 2018, Cameroon is ranked 151 out of 188 countries, with 38% of the working population earning US\$3.10 (in purchasing power parity) per day or less.<sup>14</sup> The country's health system is mainly funded by private health expenditures through out-of-pocket payments which represent approximately two-thirds of total health expenditures.<sup>15</sup> Social security expenditures on health represent only 2.6% of government health expenditure. In addition, safety nets for the poor are almost non-existent: theoretically, hospitals should have a social service to provide some financial support for the needy, but in reality there is no government funding for this service, and accordingly it is often dysfunctional.

Two recent meta-analyses estimated HBV and HCV prevalence in Cameroon at 11.2% and 4.9%, respectively, in adults from the general population.<sup>3,16</sup> The south-east region also has one of the largest iatrogenic HCV epidemics in people aged over 50 years.<sup>17</sup> This explains discrepancies in estimations of HCV prevalence in the country which vary between 0.40% and 55.88% according to subpopulation type, age group and geographical location.<sup>16</sup>

Currently, Cameroon has no national viral hepatitis programme or national guidelines for screening, diagnosis, care and treatment. At the time of the present study, hepatitis testing was mainly proposed when patients presented with symptoms, or were diagnosed HIV-positive. Systematic HBV screening is recommended during antenatal care. In addition, screening for both diseases is compulsory to register for national competitive examinations for enrolment in the national police force and national school of administration. However, no specific education material on hepatitis and its prevention, care and treatment has been developed to help effectively carry out pretest and post-test counselling sessions. Specifically, no billboards were available in hospital services and, except for hepatogastroenterologists, other HCP in general have not been trained in counselling on viral hepatitis. At the beginning of the 2010s, the Cameroon Society of Gastroenterology, comprising a dozen hepatogastroenterologists, initiated a collaborative project with public health officials and researchers to promote access to hepatitis treatment. With respect to HBV infection, access to antiretroviral treatment (tenofovir or lamivudine) was initially only available within the national HIV programme. Accordingly, only HIV-HBV co-infected patients benefited from it. This policy changed in April 2014 when tenofovir prescription was allowed outside the HIV programme at a price of €6.80 per month, but only in Douala's and Yaoundé's main referral hospitals. For HCV infection, only interferon-based treatments were available in 2014. Eligibility committees set up in Yaoundé and Douala by the Ministry of Public Health in August 2012 decided which patients could access treatment, at a cost to the latter of €7500 and €11 200 (for 48 and 72 weeks, respectively, depending on treatment response), including a discount of 33% (increased to 50% in 2014) (table 1). Before initiating treatment, patients had to

**Table 1** Prices available for HBV and HCV screening and pretherapeutic tests and treatment in 2014 in Yaoundé, Cameroon

Test or treatment	Unit price (in €)	Source
<b>Hepatitis B</b>		
Screening and pretherapeutic assessment		
HBs antigene	13.9	CPC
Anti-HBc antibodies	13.9	CPC
Anti-HBs antibodies	13.9	CPC
HBe antigene	13.9	CPC
Ag HBe antibodies	13.9	CPC
Transaminases AST/ALT	10.3	CPC
Num NFS	5.9	CPC
Albumin	5.5	CPC
Biliburin	3.0	CPC
DNA hepatitis B (PCR) viral load	69.4	CPC
Gamma-GT (glutamyl-transpeptidases)	3.2	CPC
HIV serology	13.9	CPC
Hepatitis delta	29.7	CPC
Hepatic ultrasound	12.2	Hospital 1
Fibrotest (not systematically prescribed)	135.7	CPC
Electrophoresis protein (not systematically prescribed)	83	CPC
<b>Total</b>	<b>222.6–441.3</b>	
Treatment		
Tenofovir 300 mg 30 cp (monthly treatment)	6.8	Pharmacy of hospital 2 (study data)
Lamivudine 300 mg 30 cp (monthly treatment)	5.1	Pharmacy of hospital 2 (study data)
<b>Hepatitis C</b>		
Screening and pretherapeutic assessment		
Anti-HCV antibodies	13.9	CPC
Transaminases AST/ALT	10.3	CPC
Complete Blood Count	5.9	CPC
Viral load HCV	69.3	CPC
Gamma-GT (glutamyl-transpeptidases)	3.2	CPC
Biliburin	3.0	CPC
Albumin	5.5	CPC
Genotyping (not systematically prescribed)	137	CPC
Hepatic ultrasonound	12.2	Hospital 1
Electrophoresis protein (not systematically prescribed)	83	CPC
Creatinine	2.0	CPC
<b>Total</b>	<b>125–345</b>	
<b>Interferon-based treatments</b>		Roche access programme (study data)
One injection (~30%)	155	Roche access programme (study data)
One injection (~50%)	86	Roche access programme (study data)
Full treatment 48 weeks	7500	Roche access programme (study data)
Full treatment 72 weeks	11 200	Roche access programme (study data)

ALT, alanine aminotransferase; AST, aspartate aminotransferase; CPC, Centre Pasteur Yaoundé; HBV, hepatitis B virus; HCV, hepatitis C virus.

complete a full pretherapeutic assessment, which included a large number of tests for a global cost of between €220 and €440, depending on the number and nature of the tests performed (table 1).

### Study design

We conducted a qualitative sociological study combining observations and in-depth individual interviews conducted between April and September 2014, primarily

in Yaoundé. This study was part of the ANRS 12288-EVOLCAM cross-sectional mixed methods survey which aimed to study current challenges faced by Cameroon's national antiretroviral treatment programme in the care and treatment of major HIV co-infections, namely viral hepatitis and tuberculosis.<sup>18</sup>

### Data collection

Individual in-depth interviews targeted three main categories of individuals who were invited to participate in the study: (i) key stakeholders involved in the care and treatment of hepatitis, both at the national and international levels, including senior ministry of health officials and leaders of international non-governmental organisation (NGO), (ii) HCP, mainly gastroenterologists working in infectious disease departments and involved in the consultation of patients affected by viral hepatitis in three reference hospitals of Yaoundé (Hôpital Central, Hôpital Général and CHU), one private clinic in Yaoundé, and one district hospital near Yaoundé; (iii) patients consulting for hepatitis-related symptoms in two of these five facilities (Hôpital Central and Hôpital Général). In addition, observations to assess doctor-patient relationships were conducted during medical rounds in the gastroenterology ward or outpatient medical consultation spaces of these two facilities. We used a non-standardised observation guide which was drawn up after analysing the data from a first series of observations. The main items examined included time spent during the consultation, clinical history taking, medical examination, prescription, quality of doctor-patient exchanges and patient participation in the interaction. Observations of consultations in gastroenterology services were only carried out at the Hospital Central while observations of HIV consultations were conducted in both hospitals.

Study participation was proposed to patients after their consultation. Those who agreed to share their experiences and perceptions were contacted by phone to make an appointment for an interview outside of the hospital, usually at their home. The following themes were approached using a semi-structured guide: context of screening, quality of information and counselling, experience of diagnosis, risk perceptions, disclosure-related issues, costs engaged after diagnosis and difficulties encountered in seeking care and treatment. Interviews were repeated with some of the patients to obtain more insight into their social life and experience with the infection.

Before starting each interview, the purpose and implications of the study participation was explained and consent for participation and audio-recording of the interviews was obtained. All interviews were conducted in French and audio-recorded. Information about current health policies and the health system in relation to HBV and HCV, liver complications and associated costs, was also collected through national and international reports and press.

### Analysis

We used a grounded theory approach to viral hepatitis management because it is recognised as a powerful tool to describe novel and poorly understood phenomena<sup>19</sup> and because it allowed the research team to adapt the interview and observation guides to new questions which emerged during data collection. Preliminary results were first discussed during two workshops with the qualitative researchers and then with the whole EVOLCAM team, in order to triangulate qualitative evidence with quantitative results and to incorporate new items into the data collection tools, if needed. Audio recordings of interviews and notes taken during observations were transcribed, analysed and coded manually. Codes were defined together with the research team around issues including accuracy of knowledge on hepatitis, amount and quality of information, health expenses, time between consultation and examinations, expectations of care and reference to HIV programmes. Analysis of patients' and HCP interviews was performed using the same inductive method, whereby analytical themes were generated by hypothesis and confirmed or re-evaluated by data collection. Textual analysis was then undertaken, identifying specific subthemes through occurrences and recurrences and analysis of correlations.

### Patient and public involvement

Patients were not involved in the development of the research question, the design, recruitment or implementation of this study. Results were disseminated to medical students and public health leaders during a public meeting in Yaoundé in November 2016.

## FINDINGS

### Institutional stakeholders, experts and healthcare professionals

In-depth interviews were conducted with 14 institutional stakeholders including 2 public health representatives from the Cameroon Health Ministry, 3 international experts and researchers, a total of 7 members of international and local NGO, 1 stakeholder from the media and 1 stakeholder from a pharmaceutical company. We also interviewed 14 HCP as follows: 2 nurses, 6 gastroenterologists, 3 infectious disease specialists, 1 haematologist, 1 general practitioner and 1 social worker (table 2).

### Patients

A total of 16 interviews were conducted with 12 different patients aged between 24 and 65 years. Most (9/12) were women and all had been diagnosed with chronic hepatitis (table 3): five with HBV, one with HCV, three with HBV and HIV and three with HCV and HIV. Interviews were repeated with three patients, while another patient was interviewed in the presence of her father-in-law and mother-in-law at their request. Patients typically had a low-middle class socioeconomic status, and lived in Yaoundé or its suburbs. Two were unemployed, two

**Table 2** Information on institutional stakeholders and healthcare professionals who participated in the study's semi-structured interviews (n=28)

	Position	Institution	City
<b>Institutional stakeholders</b>			
I1	Physician (gastroenterologist)	Ministry of Health	Yaoundé
I2	Public health officer	Ministry of Health	Yaoundé
I3	Hepatitis programme officer	International Organisation	Geneva
I4	Infectious disease researcher	Public Health Research	Yaoundé
I5	Virologist	Public Health Research	Yaoundé
I6	Programme leader	International NGO	Yaoundé
I7	Association leader	National NGO	Yaoundé
I8	Association leader	International NGO	Paris
I9	Programme leader	International NGO	Paris
I10	Programme manager	International NGO	Paris
I11	Physician/researcher	International NGO	Geneva
I12	Communications leader	International NGO	Paris
I13	Sales representative	Other (pharmaceutical company)	Yaoundé
I14	Head of publication	Other (National Press)	Yaoundé
<b>Healthcare professionals</b>			
H1	Nurse	Public hospital 1	Yaoundé
H2	Head nurse	Public hospital 1	Yaoundé
H3	Physician (gastroenterologist)	Public hospital 1	Yaoundé
H4	Physician (gastroenterologist)	Public hospital 1	Yaoundé
H5	Physician (gastroenterologist)	Private clinic	Yaoundé
H6	Physician (gastroenterologist)	Public hospital 2	Yaoundé
H7	Physician (gastroenterologist)	Public hospital 3	Yaoundé
H8	Physician (gastroenterologist)	Public hospital 3	Yaoundé
H9	Physician (infectious disease)	Public hospital 1	Yaoundé
H10	Physician (infectious disease)	Public hospital 2	Yaoundé
H11	Physician (infectious disease)	Public hospital 2	Yaoundé
H12	General practitioner	Public district hospital	Obala
H13	Haematologist	Public hospital 3	Yaoundé
H14	Social worker	Public hospital 1	Yaoundé

NGO, non-governmental organisation.

were students and three were retired. The others were employed as follows: one school teacher, one embroiderer, one street merchant, one pharmacy assistant and one security guard. None earned more than the average national monthly salary (approximately €50) and the majority had irregular income, as they worked in small businesses or relied on familial financial support.

### Observations in hospital wards

A total of 52 consultations in HIV services and 82 consultations in the gastroenterology wards were observed. Of the latter, 49 dealt with a viral hepatitis-related condition: 16 patients were consulting because of symptoms, 12 following positive diagnosis after a blood donation, 8 during follow-up for another disease (HIV), 6 on their own initiative in

anticipation of a marriage or a national competitive exam, 5 following antenatal screening and 2 after a screening campaign at their workplace.

### Screening occurring at an inopportune moment

According to our observations, approximately 33% (16/49) of the consultations were related to patients who discovered they had hepatitis after the onset of symptoms such as long episodes of fatigue or ascites (accumulation of fluid in the peritoneal cavity) and subsequent investigations by a gastroenterologist. The second most common reason for consultation was following diagnosis after blood donation: approximately 24% (12/49 consultations) had been referred from the hospital blood bank where they were tested positive for either HBV or HCV. In

**Table 3** Information on patients who participated in the study's semi-structured interviews (n=12)

No	Sex	Age range	Status	Circumstances of screening	Hospital	Living area	On treatment
P1	M	20–25	HBV	Blood donation	H1	Douala	None
P2	M	30–35	HBV	Symptoms	H1	Yaoundé	None
P3	F	20–25	HBV	Antenatal care	H1	Yaoundé	None
P4	F	25–30	HBV	Blood donation	H1	Obala	None
P5	F	25–30	HBV	Antenatal care	H1	Yaoundé	None
P6	F	35–40	HIV/HBV	Symptoms	H2	Yaoundé	HAART (tenofovir)
P7	M	35–40	HIV/HBV	Follow-up for HIV infection	H1	Yaoundé	HAART (tenofovir)
P8	F	35–40	HIV/HBV	Follow-up for HIV infection	H1	Yaoundé	HAART (tenofovir)
P9	F	55–60	HCV	Check-up	H1	Yaoundé	None
P10	F	35–40	HIV/HCV	Follow-up for HIV infection	H1	Adamaoua	HAART
P11	F	65–70	HIV/HCV	Follow-up for HIV infection	H2	Yaoundé	HAART
P12	F	55–60	HIV/HCV	Follow-up for HIV infection	H1	Yaoundé	HAART

F, female; H1, Hôpital central de Yaoundé; H2, Hôpital Général de Yaoundé; HAART, highly active antiretroviral treatment; M, male.

Cameroon, blood donations rely on 'family replacement', whereby the hospitalised patient's closest relatives are responsible for obtaining blood at the blood bank. They can only obtain this blood if they themselves donate their own blood to the bank. Accordingly, they are tested for hepatitis at a particularly vulnerable emotional moment.

It all started when my dad had an accident. If I hadn't been asked to give blood I wouldn't have known I was sick (...). When I got back to the blood bank to fetch my results they said to me the results were not good because she saw I was positive for hepatitis B. Well, it was a shock. (Interview, P1)

My daughter was unwell (...) Upon arrival at the hospital they noticed my child didn't have enough blood, that she was anaemic. We had to transfuse her (...) - They told me and I had to give blood, and so I did an hepatitis test. That's when I started to learn about hepatitis. I didn't even.... I didn't know this term existed. (Interview, P4)

In the two situations cited above, patients were not at all prepared for the shock announcement of positive test results. This is likely to be at least partially due to the fact that they were not part of a voluntary screening process, and therefore had not already shown concern about their own status. Another frequent circumstance of hepatitis testing was in the course of HIV follow-up. HIV-positive patients diagnosed with HBV infection could easily benefit from antiretroviral treatment including tenofovir. However, for those who discovered they were HCV-positive, the impact of the announcement was dramatic: after having struggled with HIV infection, they felt condemned again, as evidenced by the reaction of one HIV-HCV co-infected woman:

So me, I'm simply going to die? (Interview P10).

In addition, a non-negligible proportion of the patients (5/46) were consulting after HBV diagnosis during antenatal care, a very destabilising situation for future mothers given the absence of standardised and accessible prophylactic measures in Cameroon to prevent mother-to-child transmission. One physician stated:

In most hospitals screening is systematic among pregnant women but after that there's nothing! These women are dumped on us and we're asked to take care of them. Those who can afford to pay, do so; those who can't don't. (Interview H4)

### Fragmented and contradictory counselling

When HCP informed patients about their testing positive or when they interpreted laboratory results during consultation, few details were provided to the patients about hepatitis' modes of transmission, risk factors, preventive measures and therapeutic options. In some situations, the information given was alarming and even inaccurate, for example, regarding the modes of transmission of HBV:

The lab technician told me it was very, very, very contagious, that I have to be very careful because it (hepatitis B) is transmitted through sweat. (Interview P1)

Moreover, information was often contradictory, especially regarding how serious hepatitis infection can be. Patients were also disappointed with the lack of communication with healthcare professionals who, in their opinion, did not dedicate enough time to explain the infection and its evolution.

I'd like someone to explain my result to me, that I'm at this stage or that stage, but no one's ever told me. (Interview P5)

As a result, patient knowledge was usually incomplete: they only had piecemeal information gathered or remembered from their own experiences or from those of their close kin and friends, and from the radio. The absence of standardised information guidelines and lack of medical communication led to a very negative and worrying representation of life with the virus as well as a very dark prognosis.

I was always told it's a virus with no symptoms and that it always kicks in at the terminal stage; when it hits, maybe it's 'hello death'. (Interview P1)

Prevention campaigns and radio broadcasts tended to encourage this image with the aim of attracting patients to testing campaign sites.

On hepatitis day, on the radio they talked about how to get tested, that's when I understood. They talked about how you get the disease and that you have to go to the centre and get tested... go to the hospital, but that takes time. People say that it's a very risky disease, that it kills you...it kills for sure, it kills silently, that's what people say. (Interview P5)

### Moral and social destabilisation

#### Stress about infection and its evolution

When patients learnt of their hepatitis infection, they experienced great stress, manifested through anxiety. During medical consultations, as well as in interviews afterwards, patients were very affected at a psychological level, as shown in this quotation from a young man:

Honestly I am terrified by this situation (...) Just knowing you have it makes you sick. When you already know you have it, you can't think anymore that you're in good health. (Interview P1)

Patients were particularly worried about the evolution of their infection, wondering what they could expect and whether treatment was available.

When I discovered I had hepatitis I thought about going for treatment. Then I understood that you have to be sick before you can take remedies. I often wonder when I'm going to become sick, at what age. For now, I try not to contaminate other people. (Interview P2)

I only want someone to tell me how I can treat this. (Interview P10)

This strongly contrasted with the experience of HIV-HBV co-infected persons who were on an antiretroviral treatment that controls both infections. The great majority of patients considered the worst-case scenario and foresaw a fatal outcome.

When the level (of the virus) isn't high, you can be treated, but when you've already got a high level, it's difficult... you're already on the way to dying (...) When it's attacked the liver and eaten it away, what are you going to treat? (Interview father of P3)

### Fear about contaminating others

Patients were very anxious about the likelihood of contaminating close relatives. During consultations, the possibility of testing and vaccinating partners and family members and the means of prevention in general were rarely discussed, thereby increasing patient anxiety about virus transmission and the best preventive behaviours to adopt.

I suffer so bad when I think I can contaminate someone. It makes me suffer a lot and so I wonder how I can take precautions. (Interview P1)

Due to a lack of appropriate information, patients modified their daily routines and took many restrictive precautions:

When I drink water, I hide the bottle, so that no one can drink after me. (Interview P2)

One patient explained the various precautions he took to avoid sharing meals with his family and friends, while another said that he no longer slept next to one family member for fear of contamination by sweating at night.

### Disclosure of infection

Disclosing one's infection to friends and family was a difficult issue for patients. However, why and how to disclose one's infection were rarely discussed during the medical consultation. Most of the time, disclosure was necessary to solicit moral and financial support. That said, it could also lead to being left alone:

I said to my fiancée, 'you are free to go where you want'. I wanted to see what she would do. She never came back. (Interview P2)

### Catastrophic health expenditures

#### Huge expenses with little perspective of treatment

Numerous tests, according to a complex algorithm, are prescribed to assess the stage of hepatitis infection and the degree of liver damage in order to decide on the need of treatment. In Cameroon, access to care and treatment depends on patients' capacity to pay for these expensive tests, as most specialist physicians acknowledged:

Even if patients could afford treatment, patients still have to go through a very complex eligibility assessment comprising testing and confirmation, fibrotest for assessing fibrosis level and also assessment of inflammatory activity. (Interview I1)

The speed with which patients get care depends on the head of the family's pocket. (Interview H4)

The problem we have with hepatitis B is the exorbitant cost of the assessment for patients, who are most often students and cannot afford to pay, so we can't follow them. (Interview H3).

Given the exorbitant costs of tests (€150–200), very few patients were able to perform the entire pretherapeutic check-up.

What worried me the most is that the doctor said this disease is almost incurable and that you'd need enormous amounts of money, like millions (of FCFA, that is, thousands of euros). So I said to myself 'ok well if it's like that, then I'll sit at home and wait for death'. (Interview P10)

Moreover, in order to correctly assess the disease stage, all these tests need to be performed at about the same time. As patients need time to gather money, this is practically impossible.

#### Bifurcation of life trajectories

Patients were most often screened when their financial resources were already strained because of health expenditures mobilised for a hospitalised family member or for themselves and this additional bill had catastrophic consequences on their social and economic life trajectories. They had to depend on the generosity of friends, their community, village solidarity or *Tontines* (Informal Financial Sector associations). To gather money, family solidarity came under great strain:

I went crying to my older sisters. They gave me money to open a small business. I spent everything to pay for the exams. Now I am here with no money (...). If I had to rely on my husband, it'd be a waste of time. (Interview P5)

The social and economic destabilisation of hepatitis diagnosis was especially hard felt by patients starting a personal or professional project. One patient decided to cancel a wedding while another postponed having a child. In the professional domain, one young man gave up on studying at university because he knew that family expenses had already been mobilised to treat his father and therefore that he himself had to pay for his own future medical expenses.

It's not easy, I was shaken by that (*hepatitis diagnosis*) because I was told the treatment is so, so expensive. I understood that I had to find money and I realised that I couldn't think about school anymore. I wanted to start engineering school next year but when I saw that (*diagnosis*) my only thought was that I needed to find a way to take care of myself, so I thought about working in construction sites. (Interview P1)

A young professional embroider thought about selling his embroidery machine, his main working tool, in order to gather money to pay for hospital fees. The same happened to a mother of four children:

I wanted to start a dress-making business but the little money that I had was for school fees and for starting a business, and now I pay for healthcare. (Interview P5)

HBV and HCV screening is compulsory to register for most national competitive entrance examinations. A

positive diagnosis usually implies ineligibility, and thus a sudden and complete change in one's life project.

#### Therapeutic dead-end: distress and powerlessness

Recently diagnosed patients did not have access to treatment, even after finishing the pretherapeutic assessment. Moreover, exorbitant test costs, the costs of treatment—especially for HCV—were financially unbearable for the large majority of patients. Most health professionals and public health managers denounced this situation as unfair, as it produced a form of triage, as acknowledged by this physician:

Only a few people benefit from insurance schemes—like civil servants, or people whose employers have an insurance scheme—and have access to this programme (for pretherapeutic assessment), but they still have to pay for the injections. (Interview I1)

The distress generated by this therapeutic dead-end was shared by patients and HCP alike. Doctors and families were outraged as sick patients hospitalised for pathologies associated with viral hepatitis, such as liver cancer and cirrhosis, have a very poor prognosis.

It hurts when we see these young persons who are dying, when they arrive all we are left with are our eyes to cry. (Interview H3)

There was also a lack of palliative care and pain management due to insufficient equipment and human resources.

In my opinion, hepatitis care today for middle-income people...we lose them (ie, they die)... they only come when they already have complications... we lose almost all of them. (Interview H1)

Because they felt they would not receive a concrete response from hospital services, many patients sought relief through traditional or 'indigenous' medicine, which is comparatively less costly:

You see, in Africa we say that people really like going for traditional medicine because with say 100 000 FCFA (€152), you get traditional treatment. But with modern medicine, like, an exam costs 200 000 FCFA (€305), that means you need another 200 000 FCFA even before starting treatment... and that's impossible if you haven't already put it away somewhere. (Interview father of P3)

Here a patient has no other option but to go back to the village (neighbourhood) and leave it up to traditional medicine. (Interview P4)

Most patients interviewed truly appreciated and recognised the value of traditional medicine, especially its ability to alleviate the fatigue and pain associated with viral hepatitis infection. They also praised the quality of care and attentiveness provided by traditional healers.

I'm not the type to tremble when someone tells me something. I shook once and my husband supported me... today I don't have any more problems, no matter what they tell me, I try to manage according to my means and if that doesn't work, I just let it go, and from time to time there are also little pieces of bark (traditional medicine) from home that also have their value, which we take from time to time. (Interview P10)

## DISCUSSION

This is the first study to explore contexts, experiences and perspectives of both HCP and patients regarding hepatitis screening, care and treatment in Yaoundé, Cameroon, where HBV and HCV are endemic. Our findings demonstrated that in this setting, hepatitis screening does not necessarily translate into access to care and treatment, mainly because of unaffordable related costs. Four major challenges to screening and diagnosing hepatitis B and hepatitis C emerged from the patients' and HCP interviews. First, very often, hepatitis infection is discovered in difficult circumstances, when patients have already started to experience diseases symptoms or following a blood donation for a hospitalised family member. In both situations, the cumulative emotional and financial difficulties hamper patients from making sense of the diagnosis. Second, patients are not provided adequate information or counselling on risk factors and preventive measures including vaccination of relatives. This results in inadequate and stigmatising prevention practices, both from an epidemiological and clinical point of view. Little information and counselling about the chronic nature and severity of their disease and about treatment options also strongly affected patients psychologically. Third, in Cameroon, a positive diagnosis immediately leads to enormous out-of-pocket (OOP) expenditures related to the pretherapeutic check-up, which is prescribed to assess the disease stage and decide whether treatment is needed. These tests cost between €220 and €440, that is, approximately two to four times the monthly Cameroonian per capita GDP,<sup>18</sup> and are therefore considered catastrophic healthcare expenditures, likely to severely affect household welfare and push patients and their household into poverty.<sup>20 21</sup> These OOP expenditures are insurmountable barriers to accessing treatment, except for HIV-HBV co-infected patients whose antiretroviral treatment (tenofovir) is also effective for HBV. Fourth, diagnosis of chronic hepatitis translates into having to cope with an infection, and produces a rupture in a person's life trajectory. In this study, most patients interviewed were representative of the lower-middle socioeconomic class in Yaoundé: their income was irregular, coming from activities in the informal sector and they had no health insurance. The OOP expenditures required to perform pretherapeutic assessments were so high that they had detrimental consequences on all their life projects, like

weddings, childbearing, education and business development. They also contributed to increase the patients' social dependence and economic vulnerability, many risking poverty and debt and being obliged to sell their assets and/or to rely on the financial support of their social network.

Our study corroborates the results of other studies in sub-Saharan Africa pointing to serious patient destabilisation associated with HBV diagnosis, inability to pay for medical care and feelings of injustice.<sup>11</sup> However, the impact of HBV and HCV on life trajectories have rarely been documented in qualitative studies, which mainly focus on patients' representations and experiences of HBV infection,<sup>11</sup> on obstacles to linkage to care after diagnosis of HBV<sup>12</sup> and on access to HCV treatment.<sup>10</sup> In line with studies on linkage to care,<sup>4 12</sup> we identified large barriers for patients diagnosed with HBV or HCV, mainly at the structural level, including (i) a lack of adequate training of HCP which resulted in frequent misconceptions about transmission, natural history and diagnosis, (ii) a lack of simple, reliable and low-cost diagnostic tests and (iii) a lack of funding allocated to the fight against hepatitis, which resulted in unaffordable user fees for prevention, care and treatment. In contrast with other diseases such as HIV, TB or malaria, where international funding led to the expansion of prevention and care in low-resource settings, there is currently no financial mechanism dedicated to supporting prevention and treatment of viral hepatitis in these settings. Considering the size of the financial barrier to care and treatment access, this calls for a multilateral commitment from governments, funders, pharmaceutical firms, researchers and patient communities.<sup>22</sup> More specifically, our results highlight the urgent need for a comprehensive national programme in Cameroon for the screening, care and treatment of HBV and HCV. Screening uptake and access to a subsidised pretherapeutic package could be enhanced through technological innovations and point-of-care devices which may improve both geographical and financial accessibility, especially thanks to reduced costs related to transport.<sup>23 24</sup> To reach this goal, national health authorities may rely on WHO guidelines on hepatitis B and C testing which propose simplified algorithms which are easy to implement,<sup>8</sup> as well on recent WHO recommendations for the screening, care and treatment of chronic hepatitis B and C infections.<sup>25 26</sup>

Lessons from HIV should also be drawn to improve access to treatment, especially by using low-cost generic drugs and promoting subsidised treatment. While HBV treatment is currently relatively financially accessible, costing between €5.10 and €6.80 per month, we recommend free access for mono-HBV patients, as user fees reduce adherence and treatment effectiveness, something already demonstrated for HIV.<sup>27 28</sup> With respect to HCV treatment, the large decrease in prices obtained recently for DAA with the arrival of generic drugs has led to those treatments becoming very cost-effective in Cameroon.<sup>29</sup> However, at current prices (approximately

€580–€600 for a 12-week sofosbuvir-based regimen),<sup>30</sup> they will remain inaccessible for the large majority of the population if they are not subsidised.

This study has limitations. It was only conducted in Yaoundé and thus may not reflect what happens elsewhere in Cameroon, especially in rural areas. However, we can hypothesise that challenges to care access are even more severe there, as most specialists including gastroenterologists are located in Yaoundé and in Douala. In addition, the study took place in 2014 before the 2016 announcement by the Cameroonian ministry of Health about the availability of DAA.<sup>31</sup> Since then, DAA costs have substantially decreased. However, as previously seen, challenges related to access to pretherapeutic tests and to treatment are still relevant today given that current treatment prices are still far above the financial capacity of the population.

## CONCLUSION

Free or reasonably priced access to hepatitis B and C treatments in Cameroon can only be effective and efficient at reducing the hepatitis disease burden, if the screening algorithm and the whole package of pretherapeutic check-up are (i) simplified and standardised in accordance with WHO guidelines,<sup>25 26</sup> (ii) subsidised by national comprehensive policies orientated towards universal healthcare. Our results are in line with the Sustainable Development Goals.

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