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Title:

Screening for viral hepatitis B and C in Yaoundé, Cameroon: coping with uncertainty and unbearable costs

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Abstract

Objectives. To document patient and healthcare professionals (HCP) experiences with HBV and 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 analyzed according to the following themes: circumstances and perceptions surrounding hepatitis screening, counselling and disclosure, information provided by HCP on hepatitis prevention and treatment, experiences 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 healthcare professionals, 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 screening/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 renounce 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 for receiving appropriate care and patients have limited opportunity to start treatment. Free or reasonably-priced access to hepatitis treatments can only be effective and efficient at reducing the hepatitis disease burden if the whole package of pre-therapeutic check-up and treatment is standardized, simplified and subsidized by national comprehensive policies orientated towards universal health care.

Summary. Strengths and limitations of this study

- To our knowledge, this is the first study to show that hepatitis B and C screening in Cameroon is performed at an inopportune moment when patients are very vulnerable, both emotionally and economically.
- The qualitative design of the study is suitable to demonstrate why the costs of care prevent most patients from accessing much needed care and have a detrimental impact on their social and economic life trajectories.
- 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.
- This study was conducted before the announcement of arrival of Directly Acting Antivirals in Yaoundé. However challenges related to access to pre-therapeutic tests and then to treatment remain.

Introduction

According to the 2017 WHO Global hepatitis report [1], 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 more than 8% of the population in West and Central Africa, reaching 15% in some areas [2]. HCV infection is less evenly distributed with prevalences ranging from 1% in Senegal to 6.1% in Burkina Faso [3].

HBV and HCV are blood-borne infections but their main routes of transmission in Sub-Saharan Africa differ [4]. HBV is mainly transmitted at birth from mother to child (vertical transmission), during childhood through contacts 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 [5]. HBV and HCV disease progression leads to liver fibrosis, cirrhosis and hepatocellular carcinoma [6]. Antiviral treatments for HBV (e.g., Tenofovir®) and direct acting antivirals (DAA) for HCV can control viral replication, prevent disease-associated complications and even cure HCV [1]. 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 [4]. Most countries in the region lack national hepatitis prevention and treatment programs. Vaccination against HBV is included in immunisation programs but coverage is poor [1]. Immunisation at birth, which is now recommended to reduce vertical transmission, has only been adopted in a few countries [7]. Screening is suboptimal and late diagnosis (i.e. when symptoms appear) is extremely frequent [4]. 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. Upon the first resolution adopted in 2010 by the World Health Assembly which called for interventions for both prevention and control of viral hepatitis, the World Health Organization provided international guidelines for viral hepatitis screening and drew attention on this "urgent public health matter" [1], [8]. In addition, following the Dakar Call in July 2011 [9], healthcare professionals (HCP) in Africa advocated for mobilization to fight against viral hepatitis in the continent and collaborations involving health professionals and societies of gastroenterologists continue to grow today.

Despite the fact that HBV and HCV bring acute and complex challenges to HCP, patients, and health systems in general in Sub-Saharan African countries, most of these challenges remain dramatically under-studied. Comprehensive assessments of the circumstances and experiences of patients and HCP surrounding diagnosis, counselling and care for both diseases are sparse [10]–[12], especially in countries with poor access to related medical care. In this study, we aimed to document the circumstances and perceptions surrounding HBC and HCV screening and counselling, as well as the experiences regarding 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

In Cameroon, two recent meta-analyses estimated HBV and HCV prevalence at 11.2% and 4.9%, respectively, in adults of the general population [3], [13]. The south-east region of the country also has one of the largest iatrogenic HCV epidemics in people over 50 [14]. This explains discrepancies in estimations of HCV prevalence in Cameroon which vary between 0.40 and 55.88% according to subpopulation type, age group and geographical location [13].

Currently, the country has no national viral hepatitis program or national guidelines on screening, care and treatment for these infections. At the time of this study, hepatitis testing was mainly proposed when patients presented with symptoms, or were diagnosed HIV-positive. HBV screening was systematically proposed during antenatal care. In addition, screening for both diseases was compulsory to register for national competitive examinations for enrolment in the national police force and national school of administration. At the beginning of the 2010s, the Cameroon Society of Gastroenterology, involving a dozen of hepato-gastroenterologists, 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 program. Accordingly, only HIV-HBV coinfected patients benefitted from it. This policy changed in April 2014 when Tenofovir® prescription was allowed outside the HIV program at a price of 6.8 euros per month, but only in Douala and Yaoundé. 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 patient of 7,500 euros and 11,200 euros (for 48 weeks and 72 weeks, respectively, depending on treatment response), including a discount of 33% (extended to 50% in 2014) (See Table 1). Before initiating treatment, patients had to complete a full pre-therapeutic 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 (see Table 1).

Study design

We conducted a qualitative sociological study combining observations and in-depth individual interviews 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 program in the care and treatment of major HIV co-infections, namely viral hepatitis and tuberculosis [15].

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 international and national level, including senior ministry of health officials and leaders on international NGOs, ii) healthcare professionals, mainly gastroenterologists working 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.

Study participation was proposed to patients after their consultation. Those who agreed to share their experiences and perceptions were contacted by phone to fix an appointment for an interview outside of the hospital, usually at their home. Interviews were repeated with some of the patients to obtain more insight into their social life and experience with the infection. 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. All interviews were conducted in French and audio-recorded with participant authorisation. Moreover, 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 as well as national and international press.

Analysis

We used a grounded theory approach to viral hepatitis management as it is recognised as a powerful tool to describe novel and poorly understood phenomena [16] 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 soundness of knowledge on hepatitis, amount and quality of information, health expenses, time taken between consultation and exams, expectations of care, reference to HIV programs. Textual analysis was then undertaken, identifying specific sub-themes 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 conduct of this study. The results of this study were disseminated to medical students and public health responsible 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 of the Health Ministry, 3 international experts and researchers, 7 members of international or local NGO and 2 other pertinent stakeholders (media, pharmaceutical company). We also interviewed 14 healthcare professionals: two nurses, six gastroenterologists, three infectious disease specialists, one haematologist, one general practitioner and one 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 a diagnosis of chronic hepatitis (Table 3): 5 with HBV, 1 with HCV, 3 with HBV and HIV and 3 with HCV and HIV. Interviews were repeated with three patients, while another patient was interviewed with her father and mother-in-law present at their request. Patients typically had a low-middle class socioeconomic status, and lived in Yaoundé or its suburbs. Their occupational status included the following: students (2), retired (3), school teacher (1), embroider (1), street merchant (1), pharmacy assistant (1), security guard (1). None earned more than the average national monthly salary (50€) and the majority had irregular income, as they worked in small business or relied on family contributions.

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 like 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 Cameroon, blood donations rely on "family replacement" whereby the hospitalized 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 (…) when we arrived 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 a HIV-HCV coinfected 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 destabilizing situation for future mothers given the absence of standardized 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 also deplored 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 those of their close kin and friends, and from the radio. The absence of standardized 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 destabilization

Stress about infection and its evolution

When patients learned of their hepatitis infection, they experienced great stress, which manifested itself in 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 coinfected persons who were following an antiretroviral treatment that can control 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 are prescribed to assess the stage of hepatitis infection and the degree of liver damage in order to decide upon the need of treatment. In Cameroon, access to care and

treatment depend on patients' capacity to pay for these tests, as most specialist physicians acknowledged:

> 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 check-ups 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 €), it was very rare that patients were able to perform the entire pre-therapeutic 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, i.e. 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 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 mobilized for a hospitalized 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 destabilization 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 mobilized 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 woman, 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 health care. (Interview P5)

HBV and HCV screening is compulsory to register at 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 pre-therapeutic check-up. Besides exorbitant test costs, the costs of treatment, especially for HCV, were 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 program [for pre-therapeutic 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 hospitalized 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 [i.e., they die]… they only come when they already have complications… we lose almost all of them (Interview H1).

Because they feel they will not receive a concrete response from hospital services, many patients seek 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 recognized 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 healthcare professionals 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 offer the opportunity to subsequently enter into 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 hospitalized 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 pre-therapeutic check-up, which is prescribed to assess the disease stage and decide whether treatment is needed. These tests cost between 220 to 440 euros (i.e., approximately 5 to 8 times Cameroon's average monthly salary) [10]. Such OOP expenditures become unsurmountable barriers to accessing treatment, except for HIV-HBV coinfected patients whose antiretroviral treatment (Tenofovir) is also effective for HBV. Fourth, diagnosis of chronic hepatitis not only means coping with an infection but also produces a rupture in a person's life trajectory. In this study, 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 out-of-pocket expenditures required to perform the pre-therapeutic check-up were so high that they had detrimental consequences on all their life projects, for example weddings, child bearing, education and business development. They also contributed to increase their social dependence and economic vulnerability, with patients risking poverty and debt, 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 [11]. 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 [11], on obstacles to linkage to care after diagnosis of HBV [12] and on access to HCV treatment [10]. In line with studies on linkage to care [4] [12], 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 regarding 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 results 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 [17]. 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 subsidized pre-therapeutic package could be enhanced through technological innovations and point-of-care devices at a reduced cost [18], [19]. To reach this goal, lessons from HIV should be drawn. To improve access to care, the use of low-cost generic drugs and subsidized treatment should also be promoted. While HBV treatment is currently relatively financially accessible, costing between 5.10 to 6.80 euros per month, we recommend free access for mono-HBV patients, as user fees reduce adherence and treatment effectiveness, something already demonstrated for HIV [20], [21]. With respect to HCV treatment, the large decrease in prices obtained recently for DAA with the arrival of generics drugs have led to those treatments becoming very cost-effective in Cameroon [22]. However, at current prices (approximately 580-600 euros for a 12-week Sofosbuvir-based regimen)[23], such treatments will remain inaccessible for the large majority of the population if they are not subsidized.

This study has limitations. It was only conducted in Yaoundé and thus does not reflect what happens elsewhere in Cameroon, especially in rural areas. However, we can hypothesize

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 future availability of DAA [24]. Since then, DAA costs have substantially decreased. However, as previously seen, challenges related to access to pre-therapeutic tests and then to treatment remain, as current prices are still far above the financial capacity of the population.

Conclusion. Free or reasonably-priced access to hepatitis treatments in Cameroon can only be effective and efficient at reducing the hepatitis disease burden, if the whole package of pre-therapeutic check-up and treatment is standardized, simplified and subsidized by national comprehensive policies orientated towards universal health care. Our results are in line with the Sustainable Development Goals.

Contributors

FC, DNN, PET participated in the collection of data. FC and SB were responsible for data analysis and interpretation of results and FC wrote the first draft of the manuscript. SB, PC, DNN, CK and LV contributed to reviewing the manuscript. SB, LV and CK were involved in the design and implementation of the ANRS EVOLCam survey. CK, LV were the principal investigators of the survey. All authors approved the final version of the manuscript. All authors had full access to all of the data in the study and take responsibility for the integrity of this data, as well as the accuracy of the data analysis.

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Competing interests

None declared.

Ethics approval

The Ethics Review Board of the Ministry of Public Health of Cameroon granted ethical approval for this study. Patients and health professionals gave informed consent prior to interviews and observations.

Data sharing statement

No additional data available.

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Tables

Table 1. Prices of the tests and treatments available for HBV and HCV screening and treatment in 2014 in Yaoundé, Cameroon

Tests or treatment	Unit Price (in euros)	Source
Hepatitis B		
Screening and pre-therapeutic assessment		
HBs Antigene*	13.9	Centre Pasteur Yaoundé (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
TOTAL	**222.6 - 441.3**	
Treatment		
Tenofovir 300 mg 30cp (monthly treatment)	6.8	Pharmacy of Hospital 2 (study data)
Lamivudine 300 mg 30cp (monthly treatment)	5.1	Pharmacy of Hospital 2 (study data)
Hepatitis C		
Screening and pre-therapeutic assessment		
Anti HCV antibodies*	13.9	Centre Pasteur Yaoundé
Transaminases AST/ALT*	10.3	CPC
Num NFS*	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
TOTAL	**125 – 345**	
Treatment		
Interferon-based treatments		***Roche Access program (study data)***
One injection (-30%)	155	Roche Access program (study data)
One injection (-50%)	86	Roche Access program (study data)
Full treatment 48 weeks	7,500	Roche Access program (study data)
Full treatment 72 weeks	11,200	Roche Access program (study data)

Table 2. Information on institutional stakeholder and healthcare professionals who participated in the study's semi-structured interviews (N=28)

	Position	Institution	City
Institutional actors			
I1	Physician (gastroenterologist)	Ministry of Health	Yaoundé
I2	Public health officer	Ministry of Health	Yaoundé
I3	Hepatitis Program	International Organization	Geneva
I4	Infectious Disease Researcher	Public Health Research	Yaoundé
I5	Virologist	Public Health Research	Yaoundé
I6	Program leader	International NGO	Yaoundé
I7	Association leader	National NGO	Yaoundé
I8	Association leader	International NGO	Paris
I9	Program leader	International NGO	Paris
I10	Program manager	International NGO	Paris
I11	Physician/ researcher	International NGO	Geneva
I12	Communication leader	International NGO	Paris
I13	Sale Representative	Other (Pharmaceutical company)	Yaoundé
I14	Head of Publication	Other (National Press)	Yaoundé
Health care professionals			
H1	Nurse	Public Hospital-1	Yaoundé
H2	Nurse Major	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

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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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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 HBV and 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 pre-therapeutic assessment package are simplified, standardized, and subsidized by comprehensive national policies orientated towards universal health care.

Summary. 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 HCP 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 Directly Acting Antivirals in Yaoundé, the challenges related to access to pre-therapeutic tests and to treatment are still relevant today.

Introduction

According to the 2017 WHO Global hepatitis report [1], 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 more than 8% of the population in West and Central Africa, reaching 15% in some areas [2]. HCV infection is less evenly distributed with prevalences ranging from 1% in Senegal to 6.1% in Burkina Faso [3].

HBV and HCV are blood-borne infections but their main routes of transmission in Sub-Saharan Africa differ [4]. 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 [5]. HBV and HCV disease progression leads to liver fibrosis, cirrhosis and hepatocellular carcinoma [6]. Antiviral treatments for HBV (e.g., Tenofovir®) and direct acting antivirals (DAA) for HCV can control viral replication, prevent disease-associated complications and even cure HCV [1]. 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 [4]. Most countries in the region lack national hepatitis prevention and treatment programmes. Vaccination against HBV is included in immunisation programmes but coverage is poor [1]. Immunisation at birth, which is now recommended to reduce vertical transmission, has only been adopted in a few countries [7]. Screening is suboptimal and late diagnosis (i.e. when symptoms appear) is extremely frequent [4]. 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, the World Health Organization provided international guidelines for viral hepatitis screening and drew attention to this "urgent public health matter" [1], [8]. In addition, following the Dakar Call in July 2011 [9], healthcare professionals (HCP) in Africa advocated for mobilization 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 under-studied. Comprehensive assessments of the circumstances and experiences of patients and HCP in terms of diagnosis, counselling and care for both diseases are sparse [10]–[12], 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 1354 USD per capita in 2015 and a literacy rate of 80% in young adults (15-24 years) [13]. 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 3.10 USD (in purchasing power parity) per day or less [14]. 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 [15]. 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 [3], [16]. The south-east region also has one of the largest iatrogenic HCV epidemics in people over 50 [17]. 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 [16].

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 pre- and post-test counselling sessions. Specifically, no billboards were available in hospital services and, except for hepato-gastroenterologists, 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 hepato-gastroenterologists, 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 coinfected patients benefitted from it. This policy changed in April 2014 when Tenofovir® prescription was allowed outside the HIV programme at a price of 6.80 euros 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 7,500 euros and 11,200 euros (for 48 weeks and 72 weeks, respectively, depending on treatment response), including a discount of 33% (increased to 50% in 2014) (See Table 1). Before initiating treatment, patients had to complete a full pre-therapeutic 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 (see 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 [18].

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 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 using during medical rounds in the gastroenterology ward or outpatient medical consultation spaces of these two facilities. We used a non-standardized observation guide which was drawn up after analyzing the data from a first series of observations. The main items examined included time spent during the consultation, anamnesis, 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 [19] 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 sub-themes 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: two nurses, six gastroenterologists, three infectious disease specialists, one haematologist, one general practitioner and one 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): 5 with HBV, 1 with HCV, 3 with HBV and HIV and 3 with HCV and HIV. Interviews were repeated with three patients, while another patient was interviewed in the presence of her father 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, 2 were students and 3 were retired. The other were employed as follows: 1 school teacher, 1 embroiderer, 1 street merchant, 1 pharmacy assistant, and 1 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 like 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 Cameroon, blood donations rely on "family replacement" whereby the hospitalized 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 coinfected 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 destabilizing situation for future mothers given the absence of standardized 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 standardized 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 destabilization

Stress about infection and its evolution

When patients learned 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 coinfected 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 upon 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 pre-therapeutic 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, i.e. 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 mobilized for a hospitalized 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 destabilization 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 mobilized 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 health care. (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 pre-therapeutic 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 pre-therapeutic 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 hospitalized 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 [i.e., 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 recognized 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 healthcare professionals 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 hospitalized 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 pre-therapeutic check-up, which is prescribed to assess the disease stage and decide whether treatment is needed. These tests cost between 220 to 440 euros i.e., approximately 2 to 4 times the monthly Cameroonian per-capita gross domestic product [18], and are therefore considered catastrophic healthcare expenditures, likely to severely affect household welfare and push patients and their household into poverty [20], [21]. These OOP expenditures are insurmountable barriers to accessing treatment, except for HIV-HBV coinfected patients whose antiretroviral treatment (Tenofovir) is also effective for HBV. Fourth, diagnosis of chronic hepatitis not only translates into having to cope with an infection, it also 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 out-of-pocket expenditures required to perform pre-therapeutic assessments were so high that they had detrimental consequences on all their life projects, like weddings, child bearing, 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 [11]. 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 [11], on obstacles to linkage to care after diagnosis of HBV [12] and on access to HCV treatment [10]. In line with studies on linkage to care [4] [12], 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 [22]. 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 subsidized pre-therapeutic package could be enhanced through technological innovations and point-of-care devices which may improve both geographical and financial accessibility, especially thanks to reduced indirect costs related to transport [23], [24]. To reach this goal, national health authorities should rely on WHO guidelines on hepatitis B and C testing which propose simplified algorithms which are easy to implement [25], as well on recent WHO recommendations for the screening, care and treatment of chronic hepatitis B and C infections [26], [27].

Lessons from HIV should also be drawn to improve access to treatment, especially by using low-cost generic drugs and promoting subsidized treatment. While HBV treatment is currently relatively financially accessible, costing between 5.10 to 6.80 euros per month, we recommend free access for mono-HBV patients, as user fees reduce adherence and treatment

effectiveness, something already demonstrated for HIV [28], [29]. With respect to HCV treatment, the large decrease in prices obtained recently for DAA with the arrival of generic drugs have led to those treatments becoming very cost-effective in Cameroon [30]. However, at current prices (approximately 580-600 euros for a 12-week Sofosbuvir-based regimen)[31], they will remain inaccessible for the large majority of the population if they are not subsidized.

This study has limitations. It was only conducted in Yaoundé and thus does not reflect what happens elsewhere in Cameroon, especially in rural areas. However, we can hypothesize 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 [32]. Since then, DAA costs have substantially decreased. However, as previously seen, challenges related to access to pre-therapeutic 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 pre-therapeutic check-up are i) simplified and standardized in accordance with WHO guidelines [26], [27], ii) subsidized by national comprehensive policies orientated towards universal health care. Our results are in line with the Sustainable Development Goals.

Contributors

FC, DNN, PET participated in the collection of data. FC and SB were responsible for data analysis and interpretation of results and FC wrote the first draft of the manuscript. SB, PC, DNN, CK and LV

contributed to reviewing the manuscript. SB, LV and CK were involved in the design and implementation of the ANRS EVOLCam survey. CK and LV were the principal investigators of the survey. All authors approved the final version of the manuscript. All authors had full access to all of the data in the study and take responsibility for the integrity of this data, as well as the accuracy of the data analysis.

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Competing interests

None declared.

Ethics approval

The Ethics Review Board of the Ministry of Public Health of Cameroon granted ethical approval for this study. Patients and health professionals gave informed consent prior to interviews and observations.

Data sharing statement

No additional data available.

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Tables

Table 1. Prices of available for HBV and HCV screening and pre-therapeutic tests and treatment in 2014 in Yaoundé, Cameroon

Tests or treatment	Unit Price (in euros)	Source
Hepatitis B		
Screening and pre-therapeutic assessment		
HBs Antigene*	13.9	Centre Pasteur Yaoundé (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
TOTAL	**222.6 - 441.3**	
Treatment		
Tenofovir 300 mg 30cp (monthly treatment)	6.8	Pharmacy of Hospital 2 (study data)
Lamivudine 300 mg 30cp (monthly treatment)	5.1	Pharmacy of Hospital 2 (study data)
Hepatitis C		
Screening and pre-therapeutic assessment		
Anti HCV antibodies*	13.9	Centre Pasteur Yaoundé
Transaminases AST/ALT*	10.3	CPC
Num NFS*	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
TOTAL	**125 – 345**	
Treatment		
Interferon-based treatments		***Roche Access program (study data)***
One injection (-30%)	155	Roche Access program (study data)
One injection (-50%)	86	Roche Access program (study data)
Full treatment 48 weeks	7,500	Roche Access program (study data)
Full treatment 72 weeks	11,200	Roche Access program (study data)

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

	Position	Institution	City
Institutional stakeholders			
I1	Physician (gastroenterologist)	Ministry of Health	Yaoundé
I2	Public health officer	Ministry of Health	Yaoundé
I3	Hepatitis Programme Officer	International Organization	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
Healthcare professionals			
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

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

No	S	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

M=Male; F=Female; HAART= Highly Active Antiretroviral Treatment; H1= Hôpital central de Yaoundé; H2=Hôpital Général de Yaoundé

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

	Page/line no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	page 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	page 2
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	page 3; last § and page 4 2nd §
Purpose or research question - Purpose of the study and specific objectives or questions	page 2, 2nd §
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	page 8
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	page 6
Context - Setting/site and salient contextual factors; rationale**	pages 4-5
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	page 7
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	page 7
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	page 6, last §

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	page 7
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	page 9
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	page 8
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	page 8
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	page 8

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	page 10 to page 16
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	page 10 to page 16

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	page 18
Limitations - Trustworthiness and limitations of findings	page 19, first §

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	page 20
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	page 20

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
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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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Title:

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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Keywords: viral hepatitis B – viral hepatitis C – Cameroon – Qualitative study

Abstract

Objectives. To document patients' and healthcare professionals' (HCP) experiences with HBV and 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 pre-therapeutic assessment package are simplified, standardized, and subsidized by comprehensive national policies orientated towards universal health care.

Summary. 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 HCP 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 Directly Acting Antivirals in Yaoundé, the challenges related to access to pre-therapeutic tests and to treatment are still relevant today.

Introduction

According to the 2017 WHO Global hepatitis report [1], 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 more than 8% of the population in West and Central Africa, reaching 15% in some areas [2]. HCV infection is less evenly distributed with prevalences ranging from 1% in Senegal to 6.1% in Burkina Faso [3].

HBV and HCV are blood-borne infections but their main routes of transmission in Sub-Saharan Africa differ [4]. 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 [5]. HBV and HCV disease progression leads to liver fibrosis, cirrhosis and hepatocellular carcinoma [6]. Antiviral treatments for HBV (e.g., Tenofovir®) and direct acting antivirals (DAA) for HCV can control viral replication, prevent disease-associated complications and even cure HCV [1]. 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 [4]. Most countries in the region lack national hepatitis prevention and treatment programmes. Vaccination against HBV is included in immunisation programmes but coverage is poor [1]. Immunisation at birth, which is now recommended to reduce vertical transmission, has only been adopted in a few countries [7]. Screening is suboptimal and late diagnosis (i.e. when symptoms appear) is extremely frequent [4]. 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, the World Health Organization provided international guidelines for viral hepatitis screening and drew attention to this "urgent public health matter" [1], [8]. In addition, following the Dakar Call in July 2011 [9], healthcare professionals (HCP) in Africa advocated for mobilization 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 under-studied. Comprehensive assessments of the circumstances and experiences of patients and HCP in terms of diagnosis, counselling and care for both diseases are sparse [10]–[12], 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 1354 USD per capita in 2015 and a literacy rate of 80% in young adults (15-24 years) [13]. 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 3.10 USD (in purchasing power parity) per day or less [14]. 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 [15]. 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 [3], [16]. The south-east region also has one of the largest iatrogenic HCV epidemics in people over 50 [17]. 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 [16].

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 pre- and post-test counselling sessions. Specifically, no billboards were available in hospital services and, except for hepato-gastroenterologists, 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 hepato-gastroenterologists, 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 coinfected patients benefitted from it. This policy changed in April 2014 when Tenofovir® prescription was allowed outside the HIV programme at a price of 6.80 euros 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 7,500 euros and 11,200 euros (for 48 weeks and 72 weeks, respectively, depending on treatment response), including a discount of 33% (increased to 50% in 2014) (See Table 1). Before initiating treatment, patients had to complete a full pre-therapeutic 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 (see 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 [18].

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 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-standardized observation guide which was drawn up after analyzing 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 [19] 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 sub-themes 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: two nurses, six gastroenterologists, three infectious disease specialists, one haematologist, one general practitioner and one 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): 5 with HBV, 1 with HCV, 3 with HBV and HIV and 3 with HCV and HIV. Interviews were repeated with three patients, while another patient was interviewed in the presence of her father 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, 2 were students and 3 were retired. The others were employed as follows: 1 school teacher, 1 embroiderer, 1 street merchant, 1 pharmacy assistant, and 1 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 Cameroon, blood donations rely on "family replacement" whereby the hospitalized 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 coinfected 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 destabilizing situation for future mothers given the absence of standardized 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 standardized 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 destabilization

Stress about infection and its evolution

When patients learned 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 coinfected 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 upon 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 pre-therapeutic 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, i.e. 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 mobilized for a hospitalized 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 destabilization 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 mobilized 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 health care. (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 pre-therapeutic 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 pre-therapeutic 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 hospitalized 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 [i.e., 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 recognized 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 healthcare professionals 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 hospitalized 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 pre-therapeutic check-up, which is prescribed to assess the disease stage and decide whether treatment is needed. These tests cost between 220 to 440 euros i.e., approximately 2 to 4 times the monthly Cameroonian per-capita gross domestic product [18], and are therefore considered catastrophic healthcare expenditures, likely to severely affect household welfare and push patients and their household into poverty [20], [21]. These OOP expenditures are insurmountable barriers to accessing treatment, except for HIV-HBV coinfected patients whose antiretroviral treatment (Tenofovir) is also effective for HBV. Fourth, diagnosis of chronic hepatitis not only translates into having to cope with an infection, it also 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 out-of-pocket expenditures required to perform pre-therapeutic assessments were so high that they had detrimental consequences on all their life projects, like weddings, child bearing, 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 [11]. 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 [11], on obstacles to linkage to care after diagnosis of HBV [12] and on access to HCV treatment [10]. In line with studies on linkage to care [4] [12], 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 [22]. 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 subsidized pre-therapeutic package could be enhanced through technological innovations and point-of-care devices which may improve both geographical and financial accessibility, especially thanks to reduced indirect costs related to transport [23], [24]. To reach this goal, national health authorities should rely on WHO guidelines on hepatitis B and C testing which propose simplified algorithms which are easy to implement [8], as well on recent WHO recommendations for the screening, care and treatment of chronic hepatitis B and C infections [25], [26].

Lessons from HIV should also be drawn to improve access to treatment, especially by using low-cost generic drugs and promoting subsidized treatment. While HBV treatment is currently relatively financially accessible, costing between 5.10 to 6.80 euros per month, we recommend free access for mono-HBV patients, as user fees reduce adherence and treatment

effectiveness, something already demonstrated for HIV [27], [28]. 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 [29]. However, at current prices (approximately 580-600 euros for a 12-week Sofosbuvir-based regimen)[30], they will remain inaccessible for the large majority of the population if they are not subsidized.

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 hypothesize 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 [31]. Since then, DAA costs have substantially decreased. However, as previously seen, challenges related to access to pre-therapeutic 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 pre-therapeutic check-up are i) simplified and standardized in accordance with WHO guidelines [25], [26], ii) subsidized by national comprehensive policies orientated towards universal health care. Our results are in line with the Sustainable Development Goals.

Contributors

FC, DNN, PET participated in the collection of data. FC and SB were responsible for data analysis and interpretation of results and FC wrote the first draft of the manuscript. SB, PC, DNN, CK and LV

contributed to reviewing the manuscript. SB, LV and CK were involved in the design and implementation of the ANRS EVOLCam survey. CK and LV were the principal investigators of the survey. All authors approved the final version of the manuscript. All authors had full access to all of the data in the study and take responsibility for the integrity of this data, as well as the accuracy of the data analysis.

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Competing interests

None declared.

Ethics approval

The Ethics Review Board of the Ministry of Public Health of Cameroon granted ethical approval for this study. Patients and health professionals gave informed consent prior to interviews and observations.

Data sharing statement

No additional data available.

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Tables

Table 1. Prices of available for HBV and HCV screening and pre-therapeutic tests and treatment in 2014 in Yaoundé, Cameroon

Tests or treatment	Unit Price (in euros)	Source
Hepatitis B		
Screening and pre-therapeutic assessment		
HBs Antigene*	13.9	Centre Pasteur Yaoundé (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
TOTAL	**222.6 - 441.3**	
Treatment		
Tenofovir 300 mg 30cp (monthly treatment)	6.8	Pharmacy of Hospital 2 (study data)
Lamivudine 300 mg 30cp (monthly treatment)	5.1	Pharmacy of Hospital 2 (study data)
Hepatitis C		
Screening and pre-therapeutic assessment		
Anti HCV antibodies*	13.9	Centre Pasteur Yaoundé
Transaminases AST/ALT*	10.3	CPC
Num NFS*	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
TOTAL	**125 – 345**	
Treatment		
Interferon-based treatments		***Roche Access program (study data)***
One injection (-30%)	155	Roche Access program (study data)
One injection (-50%)	86	Roche Access program (study data)
Full treatment 48 weeks	7,500	Roche Access program (study data)
Full treatment 72 weeks	11,200	Roche Access program (study data)

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

	Position	Institution	City
Institutional stakeholders			
I1	Physician (gastroenterologist)	Ministry of Health	Yaoundé
I2	Public health officer	Ministry of Health	Yaoundé
I3	Hepatitis Programme Officer	International Organization	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
Healthcare professionals			
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

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

No	S	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

M=Male; F=Female; HAART= Highly Active Antiretroviral Treatment; H1= Hôpital central de Yaoundé; H2=Hôpital Général de Yaoundé

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

	Page/line no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	page 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	page 2
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	page 3; last § and page 4 2nd §
Purpose or research question - Purpose of the study and specific objectives or questions	page 2, 2nd §
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	page 8
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	page 6
Context - Setting/site and salient contextual factors; rationale**	pages 4-5
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	page 7
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	page 7
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	page 6, last §

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	page 7
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	page 9
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	page 8
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	page 8
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	page 8

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	page 10 to page 16
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	page 10 to page 16

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	page 18
Limitations - Trustworthiness and limitations of findings	page 19, first §

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	page 20
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	page 20

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

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