

Filtering inequality:
screening and
knowledge in
Senegal's
topography of
hepatitis B care



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Who has hepatitis B (in Senegal)?



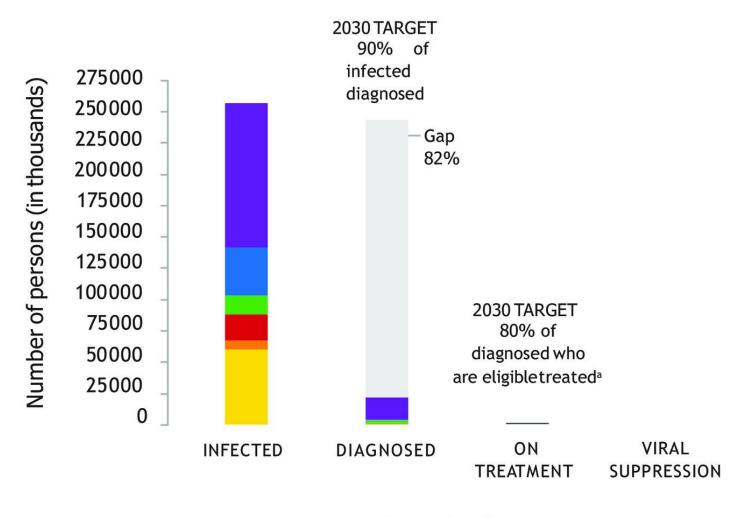
"Right now, out of the 325 million people living with viral hepatitis, more than 290 million people are living with hepatitis B or C unaware. That's 9 in 10 men, women and children who are going on about their lives not knowing they have a cancer-causing virus."

Raquel Peck, World Hepatitis Alliance









Region of the Americas

African Region

- Eastern Mediterranean Region
- European Region
- South-East Asia Region
- Western Pacific Region

Cascade of care



Discerning topographies: methodology

- Interviews with urban specialists (n~20), rural primary care nurses (n=15) and midwives (n=10) and initiators of community/public HBV communication and screening
- No extensive observation at sites of screening/referral/assessment/monitoring/treatment or following individuals through these sites
- Historical perspective: persistent high rates of HBV infection as products of prior inequalities in research and prevention – when do these start?

Senegal as hub for HBV-to-HCC research

"Geographical pathology" of HCC in Africa

1940s-50s

Barry Blumberg starts collaborating with French and Senegalese researchers on epidemiological research

Early 1970s

Late 1960s

Fred Prince and Walter Szmuness – first epidemiological research on "endemic" HBV + as risk factor for chronic liver disease

1970s

Latter 1970s: some of earliest trials of hep B vaccination (and first in "endemic" setting) Aminata Sall Diallo, in 1999, launching a pilot hep B vaccination project:

"It's [in Senegal] that the vaccine was tested. Senegal was therefore the point of departure of this hepatitis B vaccination in the world. If today Senegalese babies can finally take their turn to be protected in greater numbers, it is therefore only a just reward [un juste retour des choses]."

Specialist in internal medicine, referring to 1985 newspaper article about vaccine research in Senegal:

"I don't understand what happened afterwards... we lost a lot of time."

Methodology (cont'd)

History of research (what knowledge, how and for who?): gap in knowledge of who should be treated for HBV

+ History of prevention: delay (and therefore gap) in who has been protected from HBV (and from co-factors of liver disease)

Current intensity of West African exposure to hep B and risk of liver disease: already a marker of historical inequalities

'Thin' ethnographic window on HBV care – but glimpse of topography including 'submerged part of the iceberg,' and mechanisms of 'filtration'

Access to treatment – situated in 'filtrating topographies'

- Historical comparison with HIV in Africa:
 - ARVs arrived in landscape of widespread knowledge: AIDS symptomatology, HIV status, stakes of infection and treatment existence
 - Anthropology of access: VK Nguyen 'triage'
- HBV: knowledge scarcity and concentration
 - 'Awareness-raising' through private and periodic initiatives
 - Unsystematic screening
 - Asymptomatic infection
 - Prognostic uncertainty
 - Privatization, urban concentration and high cost of diagnostic evaluation/monitoring

Some mechanisms of filtration

- Cost of prenatal testing bundle
- Cost and urban concentration of specialist care (diagnostic bottleneck)
- Referral ambivalence:
 - Self-care advice
 - Delayed referral (postnatal)
 - Selective referral
 - Referring without conviction
 - Non-biomedical referral
- Focus on 'risk groups'
- Enacting HBV, but not for treatment

Selective referral example

- N.T.: ... what do you tell people to convince them that it's important to do the follow-up...?
- Dr. T: Well! *It depends*, eh, it depends ... on age ... on sex too, it depends on the patients you have. Because there are people who are educated, who know something about it ... but for others ... you tell them clearly that there is a disease inside you, well, sometimes ... it can manifest itself, but *it can also not* ... we explain to them, the treatment how it goes, the diet you need to follow ... *Especially the diet, because sometimes there is a lack of means, with respect to the correct treatment*...

Delayed and half-hearted referrals

- Midwives wait until women have given birth
- Doubt referral will lead anywhere (district health center for diagnostic confirmation and reinforcement of dietary advice)
- Rationale and evidence for dietary efficacy:
 - Have seen AgHBs+ revert to AgHBs-: '...so you see the value of educating them in relation, especially, to the diet they have to follow!'
 - Local aetiologies of proximity: 'Hepatitis is a problem ... here ... Because Saloum ... peanuts, there are a lot here [she repeats this]. So people eat fatty food all the time. All they eat is peanuts [...] So their whole consumption is based on peanuts. It's because of this that there is an excessive rate of positive antigens here. Liver cancer, yes, there's a lot of it.

'Awareness-raising' initiatives

- Access to treatment is not the primary goal
- Instead, the main concern is 'neutralize' -- and render as a collective problem – both HBV exposure and etiologies of liver cancer

Village with recurring cancer deaths

- "Will we let this disease destroy us? Let inaccurate beliefs dictate our actions?"
- With screening: "many cases were revealed, that's when we knew that it is hepatitis that brought this problem."

Ibrahima Gueye, Saafara Hépatites

Refuting a risk-group-based prevention strategy:

"The whole population is at risk, the numbers show it!" (2STV 2019)

Treating sexual transmission as a delicate issue:

"It cannot be said that it does not exist. It can exist. But I bring it up last, starting upstream. When someone is positive, they cannot know when they were infected. The first possibility is that they were born with it. That's to reassure [...] for the majority here in Africa, that's it. In any case, it lifts a weight. I summon the past first.

Speaking about mass vaccination as a potential source of transmission: "My goal is that the person does not feel responsible."

Implications for dialogue with African immigrants in U.S.?

- Multiple, uneven sources of information
 - Family/community histories of liver-related deaths
 - Private/personal awareness efforts: world hepatitis day, social and mass media, Gilead advertising, radio and TV, 'neotraditional' healers on youtube
 - 'Cut-and-paste' information about risk groups and sexual transmission
- Embryonic destigmatization efforts

'Local biologies' of HBV