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What can lead to late diagnosis of HIV in an illegal gold mining environment? A qualitative study at the French Guiana border with Brazil.

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TITLE:**What can lead to late diagnosis of HIV in an illegal gold mining environment? A qualitative study at the French Guiana border with Brazil.**

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French Guiana, HIV, goldmines, late diagnosis, gender, Amazonia, undocumented immigrants, access to healthcare

1 2 1 **ABSTRACT**

3 4 2 **Objective:**

5 3 The present study aimed to understand what factors can lead to late HIV diagnosis of illegal gold
6 4 miners at French Guiana's border with Brazil.
7 5

8 9 6 **Design:**

10 7 An exploratory qualitative study with in-depth interviews and observations was conducted between
11 8 November 2019 and February 2020.
12 9

13 14 10 **Setting:**

15 11 The study was conducted in the main medical healthcare service and two NGO premises in the
16 12 Oyapock border region, which is a supply area for illegal gold mining sites.
17 13

18 19 14 **Participants:**

20 15 Fifteen people living with HIV diagnosed with a CD4 count under 350/mm³ were interviewed.
21 16 Seven women and eight men participated; they were between 31 and 79 years old, and the median
22 17 time since HIV diagnosis was six years. Eight had links to illegal gold mining.
23 18

24 25 19 **Findings:**

26 20 Three key themes for late HIV diagnosis emerged: 1) The presence of economic and political
27 21 structural factors which constitute risks for this illegal activity, specifically, the repression of gold
28 22 mining sites by French armed forces and the distance from healthcare facilities; 2) Representations
29 23 of the body and of health, related to the living conditions of this population; prioritization of health
30 24 emergencies and long-term self-medication; 3) Gender roles shaping masculinity and
31 25 heterosexuality contributing to a perception of not being at risk of HIV and delaying testing.
32 26

33 34 27 **Conclusion**

35 28 This study highlights structural, group-based and individual factors that reduce access to HIV
36 29 testing and healthcare in general for a population of migrant workers in an illegal gold-mining area.
37 30 Faced with harsh living conditions and state repression, these workers develop a vision of health
38 31 which prioritizes the functionality of the body. Associated with gender roles which are partly
39 32 shaped both by the mining activity and its geographic location, this vision can lead to late HIV
40 33 diagnosis.
41 34

42 43 35 **Study strengths and limitations**

44 45 36 *Strengths*

- 46
47 37 • This is the first qualitative study on late diagnosis of HIV in illegal gold miners in
48 38 Amazonia at the French Guiana-Brazil border
- 49
50 39 • It documents a specific HIV context with few existing data
- 51
52 40 • The study shows how structural, individual and group-based factors overlap to lead to
53 41 late HIV diagnosis.
- 54
55 42 • An anthropological approach was used to study representations of health and HIV in the
56 43 goldminer population.

57 58 44 *Limitations*

- 59
60 45 • Study participants were not directly observed/interviews at goldmining camps.

1 MAIN TEXT:

2 INTRODUCTION

3 French Guiana is the region of France most impacted by HIV with a prevalence of 1.25% in the
4 general population (1). Located in continental America, it is 7 000 km from Paris. The Amazonian
5 forest represents 97% of its territory. The ethnical background of the region's approximately 270
6 000 (2) inhabitants reflect its colonial history: Creoles, indigenous peoples, Bushinengue, persons
7 from mainland France, as well as recent immigrants seeking a better life, mostly from Surinam,
8 Brazil and Haiti (3). The presence of the French State in this area is mainly visible through the
9 school system, the health system and the presence of the army, which carries out training and
10 operations (4). Compared with mainland France, the health system is under-resourced, with
11 inequalities between the coastal and inland areas. (5,6)

12 With one of the highest unemployment rates in France, and a large number of people living below
13 the poverty line, social inequalities accumulate in French Guiana, facilitating the spread of HIV (5).
14 It has been shown that social, economic, racial and gender inequalities make people more
15 vulnerable to HIV. Daily difficulties with housing, food, transport, and immigration status all
16 impact both condom negotiation and access to prevention and care (7).

17 The HIV epidemic particularly affects migrant populations (8,9). Contrary to the claims by some
18 that HIV positive migrants are already infected when they arrive, it would appear that most become
19 infected after their arrival (9,10). Despite both France and Brazil having HIV 'test and treat'
20 policies, access to healthcare in the isolated Amazonian areas of French Guiana is impacted by
21 territorial inequalities, and the epidemic continues to grow there (e.g., incidence in 2010-2015
22 increased from 32.09 to 42.35 per 10,000) (6). Among Brazilian immigrants, HIV diagnosis occurs
23 approximately 3.7 years later than in other population groups (11). HIV incidence is also increasing
24 in the neighbouring Brazilian state of Amapá (+21,2% in 2009-2019) (12).

25 The border between the two countries represents a typical marginalised border area (13) with
26 asymmetric wealth, poor living conditions, little access to education, temporary population mobility
27 and a flourishing sex trade which is often linked to nearby illegal gold mining in French Guiana
28 (14,15). Geographically distant from decision-making centres, this area remains economically and
29 politically neglected by both France and Brazil (16-18).

30 The border towns Saint-Georges (French Guiana, approximately 5 000 inhabitants) and Oiapoque
31 (Brazil, approximately 25 000 inhabitants) are located on opposite sides of the Oyapock river.
32 Oiapoque is a support base for the illegal gold mining industry located deep in the forests of French
33 Guiana. It is a primary point of arrival and departure for Brazilian gold miners. Populations here are
34 very exposed to health vulnerability (19,20), HIV treatment being available in Oiapoque only since
35 2019.

36 Approximately 10 000 gold miners work in the estimated 600 gold mining sites in French Guiana
37 (21). The region has mostly small- and medium-scale artisanal mining operations, the majority of
38 which are illegal (called *garimpos*), with workforces comprising mainly Brazilian miners (called
39 *garimpeiros*) (22–25). The social organisation of the *garimpo* is governed by norms, constraints and
40 sanctions that exist outside of state mediation (26). The *garimpeiros* associate with *donos* (bosses)

1 through very detailed oral contracts that formalise the work and the type of remuneration, mainly by
2 1 percentage (23,26). Beside work-based hazards, the *garimpos* are subject to campaigns to eradicate
3 2 illegal gold mining by the ongoing French military operation Harpie (27). These campaigns
4 3 accentuate the temporary and improvised nature this activity.
5 4

6 5 The complex socio-political contexts of illegal mining camps means that they are hard to document
7 6 from a scientific perspective as physical access is difficult for researchers (23,28). In the limited
8 7 literature available on French Guiana, medical surveys found that gold miners' working and living
9 8 conditions led to poor health, a high prevalence of infectious and non-infectious diseases including
10 9 HIV, and limited access to healthcare (29,30). In 2013, primary healthcare centres located on
11 10 French Guiana's border with Brazil observed an increase in HIV seropositivity. Brazilian patients
12 11 involved in gold mining were the most exposed. A third of the cases were diagnosed late (i.e.,
13 12 defined as a CD4 count < 350 cells / mm³) (31). Understanding the reasons for late HIV diagnosis
14 13 in this socially deprived migratory population who know little about HIV testing or prevention tools
15 14 (14,32,33) is essential to improve healthcare.

16 15 In this peripheral multilingual geographic context, using an exploratory anthropological research
17 16 approach, the present study aimed to bring new evidence to the currently scarce data on factors
18 17 leading to late HIV diagnosis. More specifically, it aimed to study how structural, individual and
19 18 group-based social constructions can lead to late HIV diagnosis by gathering and analysing data on
20 19 the experiences of patients living with HIV who are diagnosed late.
21 20

21 21 **METHODS**

22 22 **Patient and Public Involvement statement:**

23 24 No person living with HIV (PLHIV) was directly involved in the design of the study. The original
24 25 research question emerged from physicians working in the border region. The interview guide and
25 26 data collection methods were revised and validated by community health workers involved in
26 27 PLHIV medical follow-up. We had planned to present the results to participants but this was
27 28 delayed because of the COVID-19 border restrictions.
28 29

29 30 **Study design:**

30 31 Between November 2019 and February 2020, an ethnographic anthropological research study was
31 32 conducted combining observations in a medical healthcare service and NGO premises with in-depth
32 33 individual interviews at the border area between French Guiana and Brazil (Figure 1).
33 34

34 35 **Data collection:**

35 36 Of the 55 PLHIV who frequented the primary health centre for follow-up at least once in the year
36 37 preceding the study period, a panel of 21 patients with late diagnosis was identified by the referring
37 38 infectious diseases physician. Late HIV diagnosis was defined as a CD4 count below 350mm³ at
38 39 diagnosis. The maximum time between diagnosis and study inclusion was 21 years, with a median
39 40 of six years. Patients were then contacted by the healthcare mediator in charge of their medical
40 41 follow-up. Study participation was proposed during medical consultation or by phone. Fifteen of the
41 42 21 patients agreed to participate and constituted the study sample. Of these, eight had either
42 43 formerly worked in illegal gold mines in French Guiana and/or elsewhere or were/had been married

1
2 1 to a gold miner. Before the interview and before written consent was obtained, the study was
3 2 explained to the participants, and patient confidentiality and data privacy issues were clarified. The
4 3 ethical permissions granted by the Cayenne Hospital's ethical committee (UF6000/27.b) and the
5 4 French National Commission on Informatics and Liberties (# 2215827) allowed us to retrieve
6 5 specific data (CD4 count at diagnosis and low CD4 Nadir) - with patients' consent - from their
7 6 medical records.
8
9

10
11 7 Interviews lasted between 60 and 90 minutes. They were conducted in French (n=2) and/or
12 8 Portuguese (n=13) and translated simultaneously into French by a HIV community health mediator.
13 9 The following themes were discussed during the interviews: life and migration trajectory,
14 10 experience of gold mining, HIV risk perceptions, HIV screening and diagnosis history, seeking care
15 11 and treatment, social life and everyday experience with HIV. In addition, ethnographic observations
16 12 of both medical consultations and NGO HIV prevention activities were performed. An inductive
17 13 method was used for both study dimensions, whereby the interview and observation guides could be
18 14 adapted to new themes that emerged during data collection, and whereby initial protocol-defined
19 15 data collection and categorisation techniques could be modified (34).

20 16 The study was implemented in collaboration with *Oyapock coopération santé*, a French-Brazilian
21 17 project to improve access to HIV care and sexual health at the border between the two countries
22 18 (35).
23 19

24 20 **Analysis:**

25 21 Audio recordings of interviews and notes taken during observations were transcribed, coded
26 22 manually and anonymized. The exploration and production of various sources (interviews,
27 23 observations and written materials) enabled us to triangulate the data (36). Transcript analysis was
28 24 performed following thematic classification. This made it possible to identify specific sub-themes
29 25 through occurrences and recurrences and analysis of correlations. The analysis focused on data in
30 26 both French and Portuguese. The linguistic skills in Portuguese acquired by the
31 27 interviewer/researcher during fieldwork enabled her to subsequently make a transversal analysis of
32 28 the material collected.
33 29

34 30 **Ethics:** Biological results were retrieved anonymously from computerized medical charts. The
35 31 retrospective use of anonymous patient files located in patient care services was authorized by the
36 32 Cayenne Hospital's ethical committee (UF6000/27.b) and the French National Commission on
37 33 Informatics and Liberties (# 2215827). All the data collected retrospectively were anonymized in a
38 34 standardized case report form.
39 35

40 36 **RESULTS**

41 37 **Participants' characteristics:**

42 38 Seven women and eight men living with HIV participated, aged between 31 and 79 years old (Table
43 39 1). One of the 15 self-defined as homosexual. During the analysis of sharing experienced and
44 40 trajectories, a goldminer-related subgroup clearly emerged. Three men and three women were
45 41 former workers in the gold mines while two women had never worked in the industry but were/had
46 42 been married to a miner. The present analysis focuses on these 8 people. The heterogeneity of the

1 rest of the participants prevented us from being able to make a comparison with persons connected
2 to gold-mining and those who were not.

3 Nine topics emerged from the analysis of the individual interviews and observations. (Table 2).

4 **Table 1.** Summary of study participants' characteristics (N=15)

	Pseudonym	Sex	Age range	Nationality	Number of Years diagnosed HIV positive	CD4+* count at diagnosis	Low CD4+* nadir	Current occupation	Goldmining-related activity
1	Aline	F	late 30s	Brazilian	3	302	104	Cook/housekeeper	Married to a gold-miner
2	Anderson	M	late 30s	Brazilian	6	15	15	Bricklayer	Former gold-miner
3	André	M	mid 40s	French	1			Public service	no
4	Felipe	M	early 40s	Brazilian	4	200	199	Bricklayer	no
5	Ana	F	early 40s	Brazilian	4	233	233	Street Vendor	Former gold-miner
6	Janaina	F	early 60s	Brazilian	5	136	136	Farmer	Married to a gold-miner
7	João	M	mid 40s	Brazilian	6	281	105	Snack-bar manager	no
8	Julia	F	mid 40s	Brazilian	6	56	56	Housewife	no
9	Juliano	M	early 30s	Brazilian	11	<350 (Amapá, BR)	<350 (Amapá, BR)	Gardener	no
10	Oscar	M	mid 40s	French	21	Unknown at diagnosis	Unknown at diagnosis	Bricklayer	no
11	Patricia	F	late 40s	Brazilian	5	196	196	Housekeeper	no
12	Rosa	F	mid 40s	Brazilian	6	Unknown at diagnosis	Unknown at diagnosis	Manicurist	Former gold-miner
13	Sizinho	M	late 70s	Brazilian	9	103	103	Retired	Former gold-miner
14	Teresa	F	mid 40s	Brazilian	7	<350 (Amapá, BR)	<350 (Amapá, BR)	Unemployed	Former gold-miner
15	Walter	M	mid 40s	Brazilian	5	164	164	Tree pruner	Former gold-miner

5 *CD4+ in cells/mm³

8 **Table 2.** Main topics discussed during interviews with HIV-positive patients

9 **Topics**

10 Life Trajectory (childhood, professional activity, migration)

11 Goldmines, access to healthcare at gold-mine sites

12 Context of HIV diagnosis (pregnancy, HIV-positive partner, opportunistic disease)

13 Access to healthcare (HIV and other) in Brazil and French Guiana

14 Pre-diagnosis representations and knowledge of HIV

15 Sexuality (sex life, conjugality, gender role)

16 Representation of Body and of Health

1
2 Experience of living with HIV (Acceptance, discrimination, status disclosure)

3 Police and administrative problems
4

5 1

6
7 **Illegal small-scale gold mining: a specific context**

8
9 3 Illegal small-scale gold mining in French Guiana involves migration from poor regions of north and
10 4 northeast Brazil and mobility from mining camps to support bases. Oiapoque, where most of the
11 5 participants lived at the time of this study, is one such base. According to the HIV community
12 6 health mediator: “Oiapoque in its entirety was built with gold”. Despite the destruction of illegal
13 7 gold mining camps in the forest by the French government (see operation Harpie above), Brazilian
14 8 *garimpeiros* continue to build new ones. This is because compared with other types of jobs
15 9 available in the Brazilian Amazon regions, illegal small-scale gold mining in French Guiana
16 10 provides the *garimpeiros* with a lot of freedom (choice of employer, of informal contract, etc.) and
17 11 the chance to make more money. This explains why, despite the dangerousness of the work, the
18 12 hazards of production, and repressive policies, gold mining still attracts many people in search for a
19 13 better life.

20
21
22
23
24 14 I thought that there was the possibility of earning more money there; everyone was talking
25 15 about it. I went through that experience, I ‘went in’ and I worked there. *Anderson, late 30s,*
26 16 *male, bricklayer, former gold miner*

27
28 17 In remote areas of the Amazon rainforest, gold mining camps form micro-societies for places of
29 18 work, social and economic exchange, and daily life. Because of the setting of the activity, working
30 19 in an illegal mine (*garimpo* in Portuguese) involves a time commitment from several months to
31 20 years.

32
33
34 21 When I went, I didn’t get out. I did go out [for short periods] around 10 times because I
35 22 stayed there for such a long time: 10 years. *Sizinho, late 70s, male, former gold miner*

36
37 23 The six *garimpeiros* interviewed had experienced government-based repression in their mining
38 24 camps; some were arrested and then released. The complete destruction of a gold mining camp is
39 25 the most common technique used by the police and the French army. For the *garimpeiros*, this
40 26 means fleeing into the forest for several days, with the consequent risks (getting lost, no water, etc.).

41
42
43 27 When they arrive, you run; if you have time you untie your hammock, if you don't, you
44 28 leave everything behind and run; you save your skin. *Walter, mid 40s, male, tree pruner,*
45 29 *former gold miner*

46
47
48 30 The long periods of stay in the forest, moving in and out of the sites, and facing camp destruction
49 31 all represent a specific lifestyle with its own temporality. The socioeconomic environment in these
50 32 sites, their geographical isolation, and the illegality of the working practices all accentuate problems
51 33 accessing HIV prevention/testing tools and services as well as treatment.

52
53
54 34
55 35 **Gender roles, emotional and sexual relationships at the *garimpo***

56
57 36 The gold mining industry - whether practiced legally or not - impacts gender roles, sexuality and
58 37 conjugality. More specifically, the work environment and geographical distance from their homes
59 38 affects *garimpeiros*’ sexual life, not only in the camps but also when they go back to their families

1
2 1 in Brazil. Gender roles also shape relationships in the camps. The construction of masculinity
3 2 around virility is justified by the physically demanding work of extraction.

5 3 With regard to prostitution, Sizihno (*79, male, late 70s, former gold miner*) said:

7 4 There are many of them; at night there are the brothels that are open; it's a woman's work.
8 5 You drink, you dance and do your business [...] We spent a lot too: alcohol, partying,
9 6 women, all night, all night, all night long.

11 7 In addition to promoting virility, the physical and dangerous element of the work shapes
12 8 relationships with self-risk. Compared with the daily risks of mining and repression, miners put the
13 9 less visible risks into perspective, such as HIV contamination. Most of the men interviewed,
14 10 whether married or not, came on their own to the gold mining camps and saw their families between
15 11 once a month and once a year. This has an impact on sexuality, as men develop several types of
16 12 relationships including paying for sexual services and 'second home' type relationships.

20 13 Despite the very masculine environment - *garimpeiros* are almost exclusively men - women are also
21 14 present in the camps. They mostly work as cooks and sex workers; some own gold-extraction
22 15 machines. Their roles and the types of work they do also have gender-specific constraints. Three of
23 16 the women in this study were involved directly in the gold economy.

26 17 Some women go there to work in the kitchen; some women go there to work in prostitution.
27 18 There are women who aren't prostitutes, who don't go to work in prostitution, but on the
28 19 other hand they can pay for a lift [by canoe] by prostituting themselves. Everyone does
29 20 business with the person that suits them. It's very, very dangerous for a woman there, but
30 21 once you've made acquaintances, once you see who can help you, who's strong, who can
31 22 defend you, you do business with that person. *Rosa, mid 40s, female, manicurist, former
32 23 gold-miner*

36 24 In the case of women who come to the *garimpo* alone, developing intimate relationships within the
37 25 camp is a strategy for survival. Apart from prostitution, sexuality is a way to obtain services (e.g.,
38 26 ride to the nearest town), and represents a protection strategy in an environment regulated by the
39 27 threat of violence.

42 28 In terms of risk prevention, although wearing a condom can quite easily be negotiated in
43 29 transactional sex, this becomes more difficult when sexuality is part of an intimate relationship.
44 30 Couples at the camps are formed and are related to the context, For example, Walter had "*uma
45 31 namorada*", a girlfriend, in the camp where he had spent the most time; Rosa and Anderson met
46 32 each other in a camp. Couples created in camps can exist in parallel with and/or in competition with
47 33 marital relationships. Janaina discovered that her husband had an affair in the *garimpo* and this led
48 34 to their separation. During their marriage, the couple had not used any form of contraception:

52 35 No, I wasn't using anything; I also thought he wasn't with anyone there; it was a marriage,
53 36 wasn't it? *Janaina, early 60s, female, farmer*

55 37 Outside the *garimpo*, heterosexual couples - where power relations are unequal and for which social
56 38 expectations on fidelity are strong - therefore constitute a context for disease transmission. When a
57 39 married man comes home from the *garimpo*, the monogamous contract, together with economic and
58 40 emotional dependence, means hoping that the other person (whether the husband or wife) has been
59 41 faithful during the absence. This leads to a perception of being safe from potential STI infection.

2 **Having a functional body: perceiving health as the absence of symptoms**

3 Brazilians who migrate to the illegal gold mines in French Guiana in search of a better life are often
 4 uneducated. However, they have other types of knowledge and skills. As gold mining requires
 5 physical strength and endurance, health and illness are fundamental issues. *Garimpeiros* perceive
 6 that being in good health is mainly related to the proper functioning of the body. They fear disabling
 7 illnesses most and tend to minimize the importance of aches and pains. In our study, “*Tudo bem*”
 8 (‘everything’s fine’ in Portuguese), was the most common answer to questions about health during
 9 the interviews. For *garimpeiros*, less contact with doctors is greater evidence of good health. Access
 10 to outside care and medical treatment are not matters for complaint or discussion.

11 Malaria is the most frequent disease in gold mining sites. When fever and influenza-like symptoms
 12 occur, the miners self-diagnose, assume it is malaria and self-medicate to reduce seizures. In gold
 13 mining sites, the individual is responsible for their own disease management, the latter depending
 14 on what medicine is available:

15 It's a bit risky yes; some people bring their medicines with them; they have malaria drugs
 16 because there's a lot of malaria there. Sometimes people come with some anti-inflammatory
 17 drugs; there's also other people who work selling medicines, all kinds of medicines. There's
 18 no professional, no doctor there. *Rosa, mid 40's, female, manicurist, former gold miner*

19 Medications and condoms are bought in gold, and prices fluctuate. This constitutes a heavy
 20 financial burden for the workers, effectively creating a barrier to disease prevention.

21 When the symptoms do not pass, the gold diggers leave the camp to seek treatment, often when
 22 their health has already greatly deteriorated. For very serious cases, this is often difficult as the
 23 distance to the closest healthcare structure is long. Often, it is necessary to take a canoe, which
 24 further delays treatment, consequently lengthening the time spent self-medicating. Travel to
 25 hospitals only takes place “*em caso da vida o morte*” (‘when it’s a matter of life or death’), as one
 26 participant, Rosa, put it.

27 When study participants described the HIV symptoms they experienced, they often mentioned
 28 energy loss, weight loss, fever, diarrhoea, and chills. These symptoms can be mistaken for signs of
 29 other types of pathologies, such as malaria or dengue fever.

30 I'd already heard about it [HIV] before but I'd no idea what the symptoms were. If I'd
 31 known those were the symptoms, I'd have gone earlier; I'd have gone to a doctor sooner, but
 32 because I didn't know, I kept taking medicines for one thing or another... *Walter, mid 40s,*
 33 *male, pruner, former gold miner*

34 Gold miners apply the general belief that humans hide both the fact that they are mortal and the
 35 fundamental worry that comes with this, and live their lives as if the present will last forever (37).
 36 Illness, including HIV seropositivity, can jeopardise the possibility to continue their gold-extraction
 37 work:

38 Because when I got sick, I came here [Oiapoque]; everything was there [the *Garimpo*], I had
 39 to come back here. And I came here with what? With two backpacks and a child, and still
 40 sick. It is what it is. *Rosa, mid 40s, female, manicurist, former gold miner*

1
2 1 Like the other study participants, HIV diagnosis was the main reason why Rosa stopped working in
3 2 the camp. Like them, her financial situation was very difficult when interviewed.

5 3 In addition to social backgrounds and working conditions, other types of structural relationships
6 4 shape *garimpeiros'* relationships to health and to illness, including poor access to health services,
7 5 repression of the camps by the French armed forces, threats of expulsion, and other administrative
8 6 difficulties.

13 7 14 8 **Circumstances of HIV diagnosis**

15 9 Patients in our study discovered they were HIV positive in three different circumstances:
16 10 opportunistic disease, during pregnancy, and having HIV-positive partner. Gender influenced not
17 11 only the circumstance of their discovery of their positive HIV status, but also their approach to
18 12 seeking healthcare.

21 13 *Opportunistic disease*

23 14 The three male *garimpeiros* discovered they were HIV positive because long-term symptoms led
24 15 them to be hospitalized. Walter was sick for three months at the *garimpo*, and went to look for care
25 16 because his fever did not go away:

28 17 When I went to St. Laurent, I did all kinds of tests, and nothing, nothing [no positive
29 18 test results]. When a nurse asked me if I wanted to be tested for HIV, I said "Do it!".

30 19 *Walter, mid 40s, male, pruner, former gold miner*

33 20 Sizhino was also diagnosed with HIV after seeking treatment for a fever. In both cases, the medical
34 21 staff did not immediately perform a HIV test. Only later, when the other test results proved
35 22 inconclusive, did they propose this test, and in an apologetic fashion. "Don't take this the wrong
36 23 way" the nurse said to Sizinho when inviting him to do the test. This illustrates how medical care
37 24 providers in this context may still see heterosexual men as a non-risk category for HIV.

40 25 Despite discovering his wife was HIV positive during her pregnancy, Anderson never wanted to get
41 26 tested. He finally went to the hospital to get medical care when he was already in a serious
42 27 condition. Like Aline's husband, Anderson did not want to believe that his wife was infected:

45 28 What made me not believe [that my wife was HIV positive], it's because I believe - honestly
46 29 - that I wanted to continue not believing, that is to say, because I didn't want treatment. I
47 30 was traumatized by doctors you see. I didn't like doctors because I thought doctors were
48 31 doing things to us, like to lab rats, right? *Laughter*. I didn't like it, so I didn't want to know. I
49 32 thought that through the faith I had in God, I could heal myself, if possible, I believed that.

50 33 *Anderson, mid 30s, male, bricklayer, former gold miner*

54 34 For these three participants, in addition to the mine being located far from any medical facility,
55 35 having doubts about their infection, the very existence of the disease (Anderson), and a
56 36 confrontational relationship with doctors, were all factors which prevented them from getting tested
57 37 despite knowing that their wives were HIV positive.

59 38 *HIV-positive partners and pregnancy*

1
2 1 Teresa was previously a cook in different *garimpos*. While she was resting at her family's house in
3 2 Oiapoque, she received a call from the regional hospital in French Guiana. Her companion, a gold
4 3 miner, had been hospitalised in a serious condition for an opportunistic disease. When she arrived at
5 4 his bedside, she was invited to have a HIV test. Only then did she discover she was seropositive.

6 5 Rosa and Aline discovered they were HIV positive during prenatal care, and indicated that this was
7 6 very destabilizing for them as future mothers. Pregnant women have more frequent in contact with
8 7 medical institutions and our study highlights that women seem to be more likely to take up an offer
9 8 to have a test and to receive care. For our participants, discovering their seropositivity, whether
10 9 during routine check-ups (e.g., pregnancy) or during hospitalization for opportunistic diseases, was
11 10 unexpected as none thought they could be infected by HIV.

11 12 **DISCUSSION**

13 13 The illegal gold mining industry in the deep Amazonian forests of French Guiana represents one
14 14 means to finding a better life for many socially deprived people living along the French Guiana-
15 15 Brazil border. Living conditions (months spent on remote sites, the threat of repression (23)), and
16 16 the social organisation of the camps (paid sexual services, self-diagnosis and medication) increase
17 17 the likelihood of HIV infection in this population. Furthermore, access to HIV testing is difficult
18 18 (38). Our results suggest that even when the *garimpeiros* return to a supply area, they do not take
19 19 advantage of free HIV testing, as they do not perceive they are at risk, and prefer to forget about
20 20 possible at-risk behaviours they practice during their time in gold mine sites.

21 21 At the *garimpo*, gender roles determine the functions allocated to each person. Masculinity is
22 22 valorised through a specific relationship combining risk, alcohol and sexuality (39,40). The mining
23 23 activity creates a specific organization of sexuality where geographical distances influence
24 24 conjugality. Women's sexuality can be a currency for exchange (41) and intimate relationships a
25 25 strategy for safety. The risk of HIV infection is managed through social identity (42-44). It is most
26 26 likely that the women in our study were infected during their stable relationship, as this has been
27 27 reported in other contexts where female non-sex workers had the highest HIV prevalence in
28 28 informal small-scale gold mines (45). Despite the fact that advances in treatment have transformed
29 29 HIV into a controlled chronic disease, being diagnosed with HIV represented a clear biographical
30 30 disruption (46) for the *ex-garimpeiros* interviewed.

31
32 32 The physical extraction of gold requires physical strength and endurance, which produces a
33 33 particular relationship with the body. Although *garimpeiros* arrive at the mining sites in good
34 34 health, the harsh working conditions there negatively impact their health (29). Representations of
35 35 the self, health and body, all play an important role in the decision to seek (or not) medical care
36 36 (47). Disease diagnosis and treatment depend on several factors including the geographic location
37 37 of the camps. *Garimpeiros* often self-medicate, sometimes for long periods (48). When they consult
38 38 a doctor, it is only for serious issues, often requiring hospitalization (49).

39 39 In the present study, the participants said that they were surprised when they tested HIV positive
40 40 (42). None had ever thought of spontaneously doing a test. Not frequently seeking healthcare (50),

1
2 1 mistrust of the medical profession, and not perceiving risks, can all lead to late HIV diagnosis. The
3 2 latter can also occur when medical staff do not consider heterosexual patients as an at-risk
4 3 population (51,52). In our study, what emerges from the doctors and the majority of the patients, is
5 4 that most of the people invited to test agreed to do so. It would appear that preparing the person for
6 5 a potential positive HIV diagnosis by first clearly explaining the disease itself, the test, and current
7 6 treatments is fundamental, especially for pregnant women.

10 7 Using a comprehensive approach, this study shows the overlapping of structural, individual and
11 8 group-based factors in relation to HIV infection and its diagnosis, and provides a gendered
12 9 perspective of the target population's delay in seeking healthcare-seeking (53). Furthermore, it
13 10 validates the impact of illegal gold mining on this delay and on health issues in general. Indeed, in a
14 11 context where research on health issues in French Guiana is scarce, this study is the first in over
15 12 twenty years to use an ethnographic approach to investigate people living with HIV (PLVIH) in the
16 13 French Amazon from a cross-border perspective (47).

20 14 One limitation of our study is that the field work could not be performed directly with current
21 15 miners at the illegal camps, due to their inaccessibility to researchers for obvious reasons. However,
22 16 the experiences of former miners and other persons previously connected to this industry in French
23 17 Guiana, means that this survey - the first of its kind - provides excellent evidence for the situation of
24 18 gold workers there. A second limitation is potential selection bias, as participants were recruited by
25 19 medical and other healthcare staff. Furthermore, it would have been interesting to include PLHIV
26 20 living in other parts of the French Guyanese territory.

30 21 Repressive policies applied to those on the margins of society in French Guiana create a situation
31 22 where seeking healthcare becomes difficult. *Garimpeiros'* attitudes towards health and HIV need to
32 23 be understood in a context where vulnerability to infection could jeopardize their livelihood.
33 24 Advocating for a global not pathology-driven approach to healthcare is essential for this particularly
34 25 vulnerable population. Actions to fight HIV have been implemented over the last few years,
35 26 particularly at the Guiana-Brazil border area. The *Oyapock Coopération Santé* project increased the
36 27 number of tests offered and bettered the access to ARV treatment at a transnational level (35). This
37 28 community-based approach by health-mediators who are familiar with the issues involved,
38 29 reinforces these efforts and enables gold miners to access these services when they leave the
39 30 *garimpo*.

45 31 Ongoing studies, particularly on malaria (Malakit) (30), show that when tests are offered on site, or
46 32 combined with other services, people readily agree to them. Continued efforts to provide access to
47 33 health and prevention, and to integrate HIV into routine check-ups could reduce the time between
48 34 infection and diagnosis and help to reduce the HIV epidemic. These actions, which have already
49 35 borne fruit (30,35), should be perpetuated and funded in the long term. Furthermore, providing free
50 36 HIV testing, self-tests and pre-exposure prophylaxis directly in camps could also be beneficial.
51 37 Outreach focusing on educating *garimpeiros* and their partners on health and safety, especially
52 38 regarding HIV symptoms and prevention, could promote community empowerment on health
53 39 issues.

57 40 This study is exploratory. In-depth studies are needed to better understand the determinants of
58 41 delayed in testing and treating this migrant population, which is at particular risk of HIV infection.

CONCLUSION

Illegal gold mining in French Guiana involves the mobility of migrant Brazilian workers living in social deprivation living in deep forest, experiencing repression by the French state and possible eviction. These conditions generate a relationship to the body and negatively impact health and healthcare-seeking behaviours. *Garimpeiros* perceive that less contact with doctors is evidence of their good health. Social constructions of both gender - especially masculinity - and HIV risk categories, still impact access to HIV testing, leading to deteriorating health and late HIV diagnosis. Taking into account the specific difficulties *garimpeiros* face when proposing healthcare options for them, including HIV screening mobile units, would improve access to healthcare and overall health, and would reduce the HIV burden in this vulnerable population.

For peer review only

1
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3
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22 18
23 19 **Patient consent:** Oral non-opposition was obtained.

24 20
25 21 **Ethics approval:** This study was conducted in accordance with the French national public health
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27 23 strictest regulation in the world governing the protection of patients' rights and the use of health
28 24 data. In accordance with French regulations, this study was conducted without the need for consent
29 25 from an ethics committee. Moreover, it was conducted according to the principle of the reference
30 26 methodologies of France's National Commission on Informatics and Liberty (CNIL). A privacy
31 27 impact study was also conducted.

32 28
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34 30
35 31 **Data sharing statement:** The datasets generated and analysed for the current study are not
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37 33 available from corresponding author on reasonable request following prior authorization by the
38 34 CNIL.

39 35
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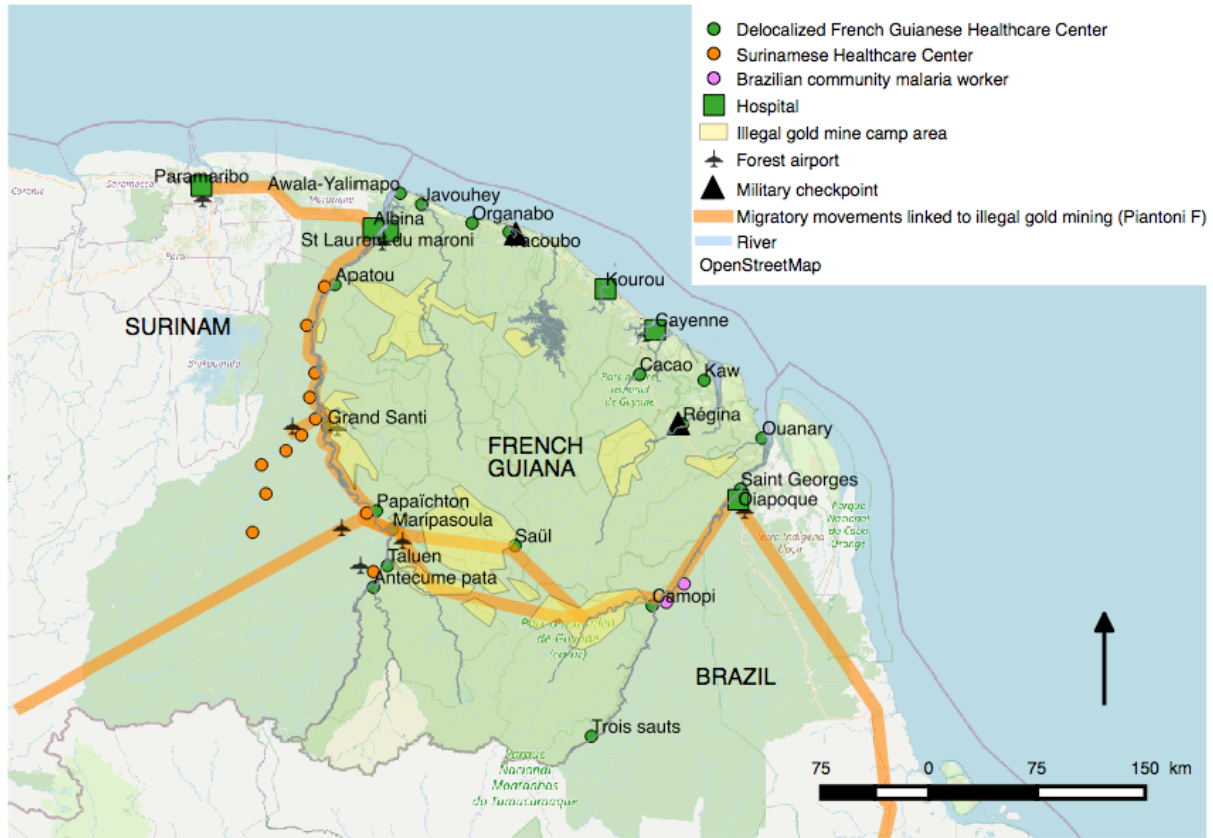
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26 **Figure 1.** Map of healthcare centers, gold mine area and migratory movements linked to illegal gold
27 mining in French Guiana which were previously reported by Piantoni F. Map was created by
28 using QGIS Geographic Information System. Open Source Geospatial Foundation Project.
29 <http://qgis.osgeo.org>
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1 2 3 4	REFERENCE : UF6000/27.b Référence interne: CIC-FORM-REG.20.11	TITRE : FORMULAIRE DE CONFORMITE DU PROJET OCCASIONS MANQUEES A LA MR-004
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17 18	Ont collaboré à la rédaction :	Visa qualité :
19 20 21	Services concernés par application: CDPS, CIC, Unité des Maladies Infectieuses et Tropicales, Médecine B, Hôpital de jour, Service Informatique	
22 23 24	Attention, seule la version numérique de ce document fait foi	



I- OBJET

L'objet de ce document est de valider la conformité du projet « *Les personnes vivant avec le VIH dépistées tardivement à la frontière Guyane-Bésil : quelles « occasions manquées » de dépistage dans les parcours de soins transfrontaliers ?* » en abrégé OccasionsManquées, à une méthodologie de référence.

II- DESCRIPTION DU PROJET : INVESTIGATEUR COORDONATEUR DE L'ETUDE

Le projet OccasionsManquées vise à comprendre/décrire les « occasions manquées » de dépistage du VIH dans la zone frontalière de la Guyane et du Brésil chez des personnes qui vivent avec le VIH diagnostiquées tardivement (associé à un dosage lymphocytaire inférieur à 350 CD4 au diagnostic) afin d'améliorer les stratégies de dépistage futures.

Prévu du 25 novembre 2019 à février 2020, le projet sera déployé dans le CDPS de Saint George d'Oyapock.

La méthodologie retenue est une étude qualitative, rétrospective, (Recherche N'Impliquant pas la Personne Humaine - RNIPH). Seront inclus les patients âgés d'au moins 18 ans qui vivent avec le VIH et diagnostiquées tardivement (un dosage lymphocytaire inférieur à 350 CD4 au diagnostic), dont aucune opposition de leur part n'a été exprimée.

En validant ce formulaire, l'investigateur coordonnateur de l'étude s'engage à ne collecter que les données strictement nécessaires et pertinentes au regard des objectifs de la recherche.

Le logiciel utilisé pour le recueil de données sera Word.

III- CATEGORISATION DU PROJET : ARC PROMOTION

OccasionsManquées est une étude qualitative, rétrospective, hors du champ de la loi Jardé. L'investigation sera faite au moyen d'entretiens dirigés impliquant éventuellement un médiateur de santé et/ou un traducteur;

L'étude ne traitera pas de données depuis des bases médico-administratives (par exemple, le SNDS) ;

Aucun appariement entre les données déjà existantes d'un même individu et issues de plusieurs centres participants ne sera nécessaire ;

L'étude ne nécessitera pas le traitement du numéro d'inscription au répertoire national d'identification des personnes physiques (NIR).

L'analyse de l'impact des opérations de traitement envisagées sur la protection des données à caractère personnel indique que le traitement ne présentera pas de risque résiduel élevé pour les droits et libertés des personnes concernées ; L'analyse d'impact peut être consultée à l'adresse : S:\DRCI\3. DPO\PIA\Validé_DPO

Le recueil du consentement se fera par la non opposition du participant ;

L'information collectée sera conforme à la méthodologie de référence MR-004

REFERENCE : UF6000/27.b Réf. interne: CIC-FORM-REG.20.11	TITRE : FORMULAIRE DE CONFORMITE DU PROJET OCCASIONS MANQUEES A LA MR-004	
Document organisationnel : <input type="checkbox"/> Document opérationnel : <input checked="" type="checkbox"/> Cycle : Réglementaire Processus : CNIL	SECTEUR EMETTEUR : CIC (UF 6000)	Page : 2/3 Date d'émission : 18/11/2019 date de révision :

Au regard de ces éléments, l'ARC PROMOTEUR de l'étude, catégorise Occasions Manquées:

- en un projet de recherche n'impliquant pas la personne humaine (RNIPH).
- En un projet relevant de la MR-004.

IV- CONFORMITE AUX PROCEDURES QUALITE – CHARGE DE PROMOTION

En validant ce formulaire, le chargé de promotion approuve la catégorisation du projet de recherche Occasions Manquées en RNIPH et son encadrement par la méthodologie de référence MR-004.

V- INSCRIPTION DE L'ETUDE DANS LE REGISTRE DES TRAITEMENTS – DPO

En validant ce formulaire, le Délégué à la Protection des Données (DPO) :

- valide la conformité du projet Occasions Manquées avec la MR-004 ;
- autorise l'ARC PROMOTEUR à inscrire le projet dans le registre des traitements des projets dont le centre hospitalier de Cayenne est promoteur. Ce registre, nommé « MR PROMOTEUR » est enregistré à l'adresse **S:\DRCI\3. DPO\MR**

ANNEXE – ENGAGEMENT DE CONFORMITE A LA MR-004

REFERENCE : UF6000/27.b Réf. interne: CIC-FORM-REG.20.11	TITRE : FORMULAIRE DE CONFORMITE DU PROJET OCCASIONS MANQUEES A LA MR-004
Document organisationnel : <input type="checkbox"/> Document opérationnel : <input checked="" type="checkbox"/> Cycle : Réglementaire Processus : CNIL	SECTEUR EMETTEUR : CIC (UF 6000)
	Page : 3/3 Date d'émission : 18/11/2019 date de révision :

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1 Déclarant <table border="1"> <tr> <td>Nom et prénom en raison sociale : CENTRE HOSPITALIER ANDREE ROSEMON</td> <td>Siège (habitat) : CIC INSERM 1424</td> </tr> <tr> <td>Service : CENTRE D'INVESTIGATION CLINIQUE 1424</td> <td>N° SIRET : 269733028 00022</td> </tr> <tr> <td>Adresse : 3 RUE DES FLAMBOYANTS, BP 6006</td> <td>Code APE : 8610Z Activités hospitalières</td> </tr> <tr> <td>Code postal : 97306 Ville : CAYENNE CEDEX</td> <td>Téléphone : 0594395385</td> </tr> <tr> <td>Adresse électronique : REGLEMENTAIRE RECHERCHE@CH-CAYENNE.FR</td> <td>Fax : 0594394872</td> </tr> </table>		Nom et prénom en raison sociale : CENTRE HOSPITALIER ANDREE ROSEMON	Siège (habitat) : CIC INSERM 1424	Service : CENTRE D'INVESTIGATION CLINIQUE 1424	N° SIRET : 269733028 00022	Adresse : 3 RUE DES FLAMBOYANTS, BP 6006	Code APE : 8610Z Activités hospitalières	Code postal : 97306 Ville : CAYENNE CEDEX	Téléphone : 0594395385	Adresse électronique : REGLEMENTAIRE RECHERCHE@CH-CAYENNE.FR	Fax : 0594394872	4 Signature <p style="font-size: small;">Je m'engage à ce que le traitement décrit par cette déclaration respecte les exigences du Règlement Général sur la Protection des Données et la loi du 6 janvier 1978 modifiée.</p> <table border="1"> <tr> <td>Personne responsable de l'organisme déclarant :</td> <td>Date le : 19-11-2019</td> </tr> <tr> <td>Nom et prénom : CLEMENT David</td> <td></td> </tr> <tr> <td>Fonction : Directeur Informatique</td> <td></td> </tr> <tr> <td>Adresse électronique : DPO@CH-CAYENNE.FR</td> <td></td> </tr> </table> <p style="font-size: x-small;">Les informations recueillies font l'objet d'un traitement informatique destiné à permettre à la CNIL l'exécution des décisions qu'elle adopte. Elles sont destinées au service de la CNIL. Certaines données figurant dans ce formulaire sont mises à disposition du public en application de l'article 11 de la loi du 6 janvier 1978 modifiée. Vous pouvez exercer votre droit d'accès et de rectification des informations que vous consultez en vous adressant à la CNIL, 3 Place de France - TSA 80715 - 75334 Paris cedex 07.</p>		Personne responsable de l'organisme déclarant :	Date le : 19-11-2019	Nom et prénom : CLEMENT David		Fonction : Directeur Informatique		Adresse électronique : DPO@CH-CAYENNE.FR			
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2 Texte de référence <p>Vous déclarez par la présente que votre traitement est strictement conforme aux règles énoncées dans la liste de référence.</p> <p>N° de référence MR-4 Recherches n'impliquant pas la personne humaine, études et évaluations dans le domaine de la santé</p>																							
3 Personne à contacter <p>Veuillez indiquer ici les coordonnées de la personne qui a complété ce questionnaire au sein de votre organisme et qui répondra aux éventuelles demandes de compléments que la CNIL pourrait être amenée à formuler.</p> <table border="1"> <tr> <td>Votre nom (prénom) : VALIER Jean-Michel</td> <td></td> </tr> <tr> <td>Service : SERVICE INFORMATIQUE</td> <td></td> </tr> <tr> <td>Adresse : 3 AVENUE DES FLAMBOYANTS BP 6006</td> <td></td> </tr> <tr> <td>Code postal : 97306 - Ville : CAYENNE CEDEX</td> <td>Téléphone : 0594394805</td> </tr> <tr> <td>Adresse électronique : DPO@CH-CAYENNE.FR</td> <td>Fax : 0594305551</td> </tr> </table> <table border="1"> <tr> <td>Raison sociale : CENTRE HOSPITALIER ANDREE ROSEMON</td> <td>N° SIRET : 269733028 00022</td> </tr> <tr> <td>Siège (habitat) : CIC INSERM 1424</td> <td>Code NAF : 8610Z Activités hospitalières</td> </tr> <tr> <td>Adresse : 3 RUE DES FLAMBOYANTS, BP 6006</td> <td></td> </tr> <tr> <td>Code postal : 97306 Ville : CAYENNE CEDEX</td> <td>Téléphone : 0594395385</td> </tr> <tr> <td>Adresse électronique : REGLEMENTAIRE RECHERCHE@CH-CAYENNE.FR</td> <td>Fax : 0594394872</td> </tr> </table>				Votre nom (prénom) : VALIER Jean-Michel		Service : SERVICE INFORMATIQUE		Adresse : 3 AVENUE DES FLAMBOYANTS BP 6006		Code postal : 97306 - Ville : CAYENNE CEDEX	Téléphone : 0594394805	Adresse électronique : DPO@CH-CAYENNE.FR	Fax : 0594305551	Raison sociale : CENTRE HOSPITALIER ANDREE ROSEMON	N° SIRET : 269733028 00022	Siège (habitat) : CIC INSERM 1424	Code NAF : 8610Z Activités hospitalières	Adresse : 3 RUE DES FLAMBOYANTS, BP 6006		Code postal : 97306 Ville : CAYENNE CEDEX	Téléphone : 0594395385	Adresse électronique : REGLEMENTAIRE RECHERCHE@CH-CAYENNE.FR	Fax : 0594394872
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Standards for Reporting Qualitative Research (SRQR)*

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

Page/line no(s).

Title and abstract

<p>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</p>	<p>Done, Page:1 Line:2</p>
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	<p>Done, Page:2 Line:1</p>

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	<p>Done, Page: 3 and 4</p>
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	<p>Done Page:4 Line:17</p>

Methods

<p>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**</p>	<p>Done Page: 4 Line: 31 Page 5 Line:11-14</p>
<p>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</p>	<p>Done Page: 5 Line: 24</p>
<p>Context - Setting/site and salient contextual factors; rationale**</p>	<p>Done Page 4 Line 31- 41</p>
<p>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**</p>	<p>Done, Page:4 Line:36</p>
<p>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</p>	<p>Done Page:5 Line: 1 to 5</p>
<p>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**</p>	<p>Done method section</p>

1 2 3 4 5	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	Done Page:5 Line: 20
6 7 8	Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Done Page: 5 Line: 36
9 10 11 12	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	Done Page:5 Line: 11
13 14 15 16	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**	Done Page: 5 Line: 21-24
17 18 19 20	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Done Page: 5 Line: 22

Results/findings

23 24 25 26	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	Done, ` results section P7-P11
27 28 29	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Done, results section

Discussion

32 33 34 35 36 37	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	Done, discussion section P11-12
38 39	Limitations - Trustworthiness and limitations of findings	Done, Page: 12 Line:12 to18

Other

42 43 44	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Done Page: 12 Line: 16
45 46	Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Done

*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.

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**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
DOI: 10.1097/ACM.0000000000000388

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BMJ Open

What can lead to late diagnosis of HIV in an illegal gold mining environment? A qualitative study at the French Guiana border with Brazil.

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Primary Subject Heading:	HIV/AIDS
Secondary Subject Heading:	Qualitative research
Keywords:	HIV & AIDS < INFECTIOUS DISEASES, Public health < INFECTIOUS DISEASES, Epidemiology < INFECTIOUS DISEASES

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TITLE:**What can lead to late diagnosis of HIV in an illegal gold mining environment? A qualitative study at the French Guiana border with Brazil.**

Charlotte Floersheim^{1,2}, Sandrine Musso³, August Eubanks⁴, Maylis Douine⁵, Bruno Spire⁴, Luis Sagaon-Teyssier⁴, Marie Claire Parriault⁵, Gabriel Girard⁴, Émilie Mosnier^{1,4}(ORCID 0000-0002-6004-3323)

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Keywords:

French Guiana, HIV, goldmines, late diagnosis, gender, Amazonia, undocumented immigrants, access to healthcare

1 2 1 **ABSTRACT**

3 4 2 **Objective:**

5 3 The present study aimed to describe the factors that lead to late HIV diagnosis in illegal gold miners
6 4 living and working at French Guiana's border with Brazil.

8 9 5 **Design:**

10 6 An exploratory qualitative study with in-depth interviews and observations was conducted between
11 7 November 2019 and February 2020.

13 8 14 9 **Setting:**

15 10 The study was conducted in the main medical healthcare service and two NGO premises in the
16 11 Oyapock border region, which is a supply area for illegal gold mining sites.

17 12 18 13 **Participants:**

19 14 Fifteen people living with HIV diagnosed with a CD4 count under 350/mm³ were interviewed. Seven
20 15 women and eight men participated. They were between 31 and 79 years old, and the median time
21 16 since HIV diagnosis was six years. Eight had links to illegal gold mining.

23 17 24 18 **Findings:**

25 19 Three key themes for late HIV diagnosis emerged: 1) The presence of economic and political
26 20 structural factors which constitute risks for this illegal activity, specifically, the repression of gold
27 21 mining sites by French armed forces and the distance from healthcare facilities; 2) Representations
28 22 of the body and of health, related to the living conditions of this population; prioritization of health
29 23 emergencies and long-term self-medication; 3) The shaping of masculinity and heterosexuality by
30 24 gender roles, contributes to a perception of not being at risk of HIV and consequent delayed HIV
31 25 testing.

33 26 34 27 **Conclusion**

35 28 This study highlights structural, group-based and individual factors that reduce access to HIV testing
36 29 and healthcare in general for migrant workers in an illegal gold-mining area in French Guiana. Faced
37 30 with harsh living conditions and state repression, these workers develop a vision of health which
38 31 prioritizes the functionality of the body. Associated with gender roles which are partly shaped both
39 32 by the mining activity and its geographic location, this vision can lead to late HIV diagnosis.

41 33 42 34 **Study strengths and limitations**

43 35 *Strengths*

- 44 36 • In-depth interviews were conducted with late-diagnosed PLHIV involved in illegal gold
45 37 mining activities.
- 46 38 • Community health workers involved in PLHIV medical follow-up revised and validated
47 39 data collection.
- 48 40 • A qualitative approach was used to study representations of health and HIV in the
49 41 goldminer population.

51 42 *Limitations*

- 52 43 • Study participants were not directly observed/interviewed at goldmining camps.

1 MAIN TEXT:

2 INTRODUCTION

3 French Guiana is the territorial region of France most impacted by HIV, with a prevalence of 1.25%
4 in the general population (1). Located in continental America, it is located 7 000 km from Paris. The
5 Amazonian forest represents 97% of its territory. The ethnical background of the region's
6 approximately 270 000 (2) inhabitants reflects its colonial history: Creoles, indigenous peoples,
7 Bushinengue, persons from mainland France, and recent immigrants seeking a better life, mostly Haiti
8 and neighbouring Surinam and Brazil (3). The presence of the French State in this area is mainly
9 visible through the schooling and health systems, and the presence of the army, which carries out
10 military training exercises and the dismantling of illegal gold mining sites (4). Compared with
11 mainland France, the health system is under-resourced, and intra-regional inequalities exist between
12 the coastal and inland areas. (5,6)

13 With one of the highest unemployment rates in France, and a large proportion of people living below
14 the poverty line, social inequalities accumulate in French Guiana, facilitating the spread of HIV (5).
15 It has been shown that social, economic, racial and gender inequalities make people more vulnerable
16 to HIV. Daily difficulties with housing, food, transport, and immigration status all impact both
17 condom negotiation and access to prevention and care (7).

18 The HIV epidemic particularly affects migrant populations (8,9). Contrary to the claims by some that
19 HIV positive migrants are already infected when they arrive in French Guiana, it would appear that
20 most become infected after their arrival (9,10). Despite France and Brazil having HIV 'test and treat'
21 policies, access to healthcare in the isolated Amazonian areas of French Guiana is impacted by
22 territorial inequalities, and the epidemic continues to grow there (e.g., incidence increased from 32.09
23 to 42.35 per 10,000 between 2010 and 2015) (6). Among Brazilian immigrants, HIV diagnosis occurs
24 approximately 3.7 years later than among other population groups (11). HIV incidence is also
25 increasing in the neighbouring Brazilian state of Amapá (+21,2% in 2009-2019) (12).

26 The border between French Guiana and Brazil represents a typical marginalised border area (13),
27 with asymmetric wealth, poor living conditions, little access to education, temporary population
28 mobility, and a flourishing sex trade which is often linked to nearby illegal gold mining in French
29 Guiana (14,15). Geographically distant from decision-making centres, this area remains economically
30 and politically neglected by both countries (16-18).

31 The border towns Saint-Georges (French Guiana, approximately 5 000 inhabitants) and Oiapoque
32 (Brazil, approximately 25 000 inhabitants) are located on opposite sides of the Oyapock river.
33 Oiapoque is a support base for the illegal gold mining industry located deep in the forests of French
34 Guiana. It is a primary point of arrival and departure for Brazilian gold miners. Populations here are
35 vulnerable to health problems and are marginalised from healthcare services (19,20). HIV treatment
36 has only been available in Oiapoque since 2019.

37 Approximately 10 000 gold miners work in the estimated 600 gold mining sites in French Guiana
38 (21). The region has mostly small- and medium-scale artisanal mining operations, the majority of
39 which are illegal (called *garimpos*), with workforces comprising mainly Brazilian miners (called
40 *garimpeiros*) (22–25). The social organisation of the *garimpo* is governed by norms, constraints and

1
2 1 sanctions that exist outside of state mediation (26). The *garimpeiros* associate with *donos* (bosses)
3 2 through very detailed oral contracts that formalise the work and the type of remuneration, which
4 3 mainly operates on a percentage basis (23,26). Beside work-based hazards, the *garimpos* are subject
5 4 to governmental campaigns to eradicate illegal gold mining through an ongoing French military
6 5 operation called Harpie (27). These campaigns accentuate the temporary and improvised nature of
7 6 *garimpos* .
8
9

10 7 The complex socio-political contexts of illegal mining camps means that they are hard to document
11 8 from a scientific perspective, as physical access is difficult for researchers (23,28). In the limited
12 9 literature available on French Guiana, medical surveys found that gold miners' working and living
13 10 conditions led to poor health, a high prevalence of infectious and non-infectious diseases including
14 11 HIV, and limited access to healthcare (29,30). In 2013, primary healthcare centres located on French
15 12 Guiana's border with Brazil observed an increase in HIV seropositivity. Brazilian patients involved
16 13 in gold mining were the most exposed. A third of the cases were diagnosed late (i.e., CD4 count <
17 14 350 cells / mm³) (31). Understanding the reasons for late HIV diagnosis in this socially deprived
18 15 migratory population who know little about HIV testing or prevention tools (14,32,33) is essential to
19 16 improve healthcare.
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24 17 In this peripheral multilingual geographic context, we implemented an exploratory qualitative
25 18 research study which aimed to add to the currently scarce data on factors leading to late HIV diagnosis
26 19 in migrant workers in French Guiana. More specifically, it aimed to study how structural, individual
27 20 and group-based social constructions can lead to late HIV diagnosis, by gathering and analysing data
28 21 on the experiences of late-diagnosed patients living with HIV.
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33 23 **METHODS**

34 24 **Patient and Public Involvement statement:**

35 25
36 26 No person living with HIV (PLHIV) was directly involved in the design of the study. The original
37 27 research question emerged from physicians working in the border region. The interview guide and
38 28 data collection methods were revised and validated by community health workers involved in PLHIV
39 29 medical follow-up. We had planned to present the results to participants but this was delayed because
40 30 of COVID-19 border restrictions.
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45 32 **Study design:**

46 33
47 34 Between November 2019 and February 2020, an ethnographic anthropological research study was
48 35 conducted combining observations in a medical healthcare service and two NGO premises with in-
49 36 depth individual interviews at the Oyapock border area between French Guiana and Brazil (Figure
50 37 1).
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54 38 **Data collection:**

55 39
56 40 Of the 55 PLHIV who frequented the primary health centre for follow-up at least once in the year
57 41 before the study period, a panel of 21 late-diagnosed PLHIV was identified by the local specialist
58 42 infectious diseases physician. Late HIV diagnosis was defined as a CD4 count below 350mm³ at
59 43 diagnosis. The maximum time between diagnosis and study inclusion was 21 years, with a median of
60 six years. Patients were contacted by the healthcare mediator in charge of their medical follow-up,

1 and were invited to participate in the study during a medical consultation or by phone. Fifteen of the
2 21 patients agreed to participate and constituted the study sample. Of these, eight had either formerly
3 worked in illegal gold mines in French Guiana and/or elsewhere, or were/had been married to a gold
4 miner. Before the interview and before written consent was obtained, the study was explained to the
5 participants, and patient confidentiality and data privacy issues were clarified.

6 Interviews lasted between 60 and 90 minutes. They were conducted in French (n=2) and/or
7 Portuguese (n=13) and translated simultaneously into French by a HIV community health mediator.
8 The following themes were discussed : life and migration trajectory, experience of gold mining, HIV
9 risk perceptions, HIV screening and diagnosis history, seeking care and treatment, social life and
10 everyday experience with HIV. In addition, ethnographic observations of both medical consultations
11 and NGO HIV prevention activities were performed. An inductive method was used for both study
12 dimensions, whereby the interview and observation guides could be adapted to new themes that
13 emerged during data collection, and whereby initial protocol-defined data collection and
14 categorisation techniques could be modified (34).

15 The study was implemented in collaboration with *Oyapock Coopération Santé*, a French-Brazilian
16 NGO project developed in collaboration with the Centre Hospitalier de Cayenne, to improve access
17 to HIV care and sexual health at the border between the two countries (35).

18 **Analysis:**

19 Audio recordings of interviews and notes taken during observations were transcribed, coded
20 manually, and anonymized. The exploration and production of various sources (interviews,
21 observations and written materials) enabled us to triangulate the data (36). Transcript analysis was
22 performed following thematic classification. This made it possible to identify specific sub-themes
23 through occurrences and recurrences and analysis of correlations. The analysis focused on data in
24 both French and Portuguese. The linguistic skills in Portuguese acquired by the interviewer/researcher
25 during fieldwork enabled her to subsequently make a transversal analysis of the material collected.

26 **Ethics:**

27 The retrospective use of anonymous patient files (including CD4 count at diagnosis and low CD4
28 Nadir) located in patient care services was authorized by the Centre Hospitalier de Cayenne's ethical
29 committee (UF6000/27.b) and the French National Commission on Informatics and Liberties
30 (# 2215827).

31 **RESULTS**

32 **Participants' characteristics:**

33 Seven women and eight men living with HIV participated. They were aged between 31 and 79 years
34 old (Table 1). One self-defined as homosexual. During the analysis of discourses on shared
35 experiences and trajectories, a goldminer-related subgroup clearly emerged. Three men and three
36 women were former workers in the gold mines, while two women were/had been married to a miner
37 (although they themselves had never worked in the industry). The present analysis focuses on these
38 eight people. The heterogeneity of the rest of the participants prevented us from being able to make
39 a comparison with persons connected to gold-mining and those who were not.

1
2 1 Nine topics emerged from the analysis of the individual interviews and observations. (Table 2).

3
4 2 **Table 1.** Summary of study participants' characteristics (N=15)

5 3 *CD4+ in cells/mm³

6
7 4
8 5
9 6 **Table 2.** Main topics discussed during interviews with HIV-positive patients

10 7
11 **Topics**

12 Life Trajectory (childhood, professional activity, migration)

13 Goldmines, access to healthcare at gold-mine sites

14 Context of HIV diagnosis (pregnancy, HIV-positive partner, opportunistic disease)

15 Access to healthcare (HIV and other) in Brazil and French Guiana

16 Pre-diagnosis representations and knowledge of HIV

17 Sexuality (sex life, conjugality, gender role)

18 Representation of Body and of Health

19 Experience of living with HIV (Acceptance, discrimination, status disclosure)

20 Police and administrative problems

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26 9 **Illegal small-scale gold mining: a specific context**

27
28 10 Illegal small-scale gold mining in French Guiana is characterized by migration from poor regions of
29 11 north and northeast Brazil to the mining areas, and by mobility between mining camps and support
30 12 bases. The town of Oiapoque is one such base. Located in Brazil, at the border with French Guiana,
31 13 this is where most of the present study participants were living at the time of the study. According to
32 14 the local HIV community health mediator: "Oiapoque in its entirety was built with gold". Despite the
33 15 destruction of illegal gold mining camps in the French Guiana forest by the French government (see
34 16 operation Harpie above), Brazilian *garimpeiros* continue to build new ones there. This is because,
35 17 compared with other types of jobs available in the Brazilian Amazon regions, illegal small-scale gold
36 18 mining in French Guiana provides *garimpeiros* a lot of freedom (choice of employer, of informal
37 19 contract, etc.) and the chance to make more money. This explains why, despite the dangerous nature
38 20 of the work, the hazards of production, and repressive governmental policies, gold mining still
39 21 attracts many people in search of a better life.

40
41
42
43
44 22 I thought that there was the possibility of earning more money there; everyone was talking
45 23 about it. I went through that experience, I 'went in' and I worked there. *Anderson, late 30s,*
46 24 *male, bricklayer, former gold miner*

47
48
49 25 In remote areas of the Amazon rainforest, gold mining camps form micro-societies for places of work,
50 26 social and economic exchange, and daily life. Because of the remote setting of the activity, working
51 27 in *garimpos* involves a time commitment from several months to years.

52
53 28 When I went, I didn't get out. I did go out [for short periods] around 10 times because I stayed
54 29 there for such a long time: 10 years. *Sizinho, late 70s, male, former gold miner*

55
56 30 The six *garimpeiros* interviewed had experienced government-based repression in their mining
57 31 camps; some were arrested and then released. The complete destruction of a gold mining camp is the
58 32 most common technique used by the police and the French army. For the *garimpeiros*, this meant

1
2 1 fleeing into the forest for several days, with consequent risks for their health and safety (getting lost,
3 2 no water, etc.).

5 3 When they arrive, you run; if you have time you untie your hammock, if you don't, you leave
6 4 everything behind and run; you save your skin. *Walter, mid 40s, male, tree pruner, former*
8 5 *gold miner*

10 6 The long periods of stay in the forest, moving in and out of the sites, and camp destruction all
11 7 represent a specific lifestyle with its own temporality. The socioeconomic environment in these sites,
12 8 their geographical isolation, and the illegality of the working practices, all accentuate existing
13 9 problems in accessing HIV prevention/testing tools and services, as well as related treatment.

17 11 **Gender roles, emotional and sexual relationships at *garimpos***

19 12 The gold mining industry - whether practiced legally or not - impacts gender roles, sexuality and
20 13 conjugality. More specifically, the work environment and geographical distance from their homes
21 14 affects *garimpeiros*' sexual life, not only in the camps but also when they go back to their families in
22 15 Brazil. Gender roles also shape relationships in the camps. The construction of masculinity around
23 16 virility is justified by the physically demanding work of extraction.

26 17 With regard to prostitution, Sizihno (*male, late 70s, former gold miner*) said:

28 18 There are many of them; at night there are the brothels that are open; it's a woman's work.
29 19 You drink, you dance and do your business [...] We spent a lot too: alcohol, partying, women,
30 20 all night, all night, all night long.

33 21 In addition to promoting virility, the physical and dangerous element of the work shapes relationships
34 22 with self-risk. Compared with the daily risks of mining and repression, miners put the less visible
35 23 risks, such as HIV contamination, into perspective. Most of the men interviewed, whether married or
36 24 not, came on their own to the gold mining camps and saw their families between once a month and
37 25 once a year. This had an impact on sexuality, as they developed several types of relationships,
38 26 including paying for sexual services and 'second home' type relationships.

41 27 Despite the very masculine environment (*garimpeiros* are almost exclusively men), women are also
42 28 present in the camps. Most work as cooks or sex workers, while some own gold-extraction machines.
43 29 Their roles and the types of work they do also have gender-specific constraints. Three of the women
44 30 in this study were involved directly in the gold economy.

47 31 Some women go there to work in the kitchen; some women go there to work in prostitution.
48 32 There are women who aren't prostitutes, who don't go to work in prostitution, but on the other
49 33 hand they can pay for a lift [by canoe] by prostituting themselves. Everyone does business
50 34 with the person that suits them. It's very, very dangerous for a woman there, but once you've
51 35 made acquaintances, once you see who can help you, who's strong, who can defend you, you
52 36 do business with that person. *Rosa, mid 40s, female, manicurist, former gold-miner*

56 37 In the case of women who come to the *garimpo* alone, developing intimate relationships within the
57 38 camp is a strategy for survival. Apart from prostitution, sexuality is a way to obtain services (e.g.,
58 39 ride to the nearest town), and represents a protection strategy in an environment regulated by the
60 40 threat of violence.

1
2 1 In terms of risk prevention, although wearing a condom can quite easily be negotiated in transactional
3 2 sex, this becomes more difficult when sexuality is part of an intimate relationship. Couples at the
4 3 camps are formed and are related to the context, for example, Walter had *uma namorada*, a girlfriend,
5 4 in the camp where he had spent the most time; Rosa and Anderson met each other in a camp. Couples
6 5 created in camps can exist in parallel with and/or in competition with marital relationships. Janaina
7 6 discovered that her husband had an affair in the *garimpo* and this led to their separation. During their
8 7 marriage, the couple had not used any form of contraception:

11
12 8 No, I wasn't using anything; I also thought he wasn't with anyone there; it was a marriage,
13 9 wasn't it? *Janaina, early 60s, female, farmer*

15 10 Outside the *garimpo*, heterosexual couples - where power relations are unequal and for which social
16 11 expectations on fidelity are strong - therefore constitute a context for disease transmission. When a
17 12 married man comes home from the *garimpo*, the monogamous contract, together with economic and
18 13 emotional dependence, means hoping that the other person (whether the husband or wife) has been
19 14 faithful during the absence. This leads to a perception of being safe from potential STI infection.

24 16 **Having a functional body: perceiving health as the absence of symptoms**

26 17 Brazilians who migrate to the illegal gold mines in French Guiana in search of a better life are often
27 18 uneducated. However, they have other types of knowledge and skills. As gold mining requires
28 19 physical strength and endurance, health and illness are fundamental issues. *Garimpeiros* perceive that
29 20 being in good health is mainly related to the proper functioning of the body. They fear disabling
30 21 illnesses most, and tend to minimize the importance of aches and pains. In our study, *Tudo bem*
31 22 ('everything's fine' in Portuguese), was the most common answer to questions about health during
32 23 the interviews. For *garimpeiros*, less contact with doctors is greater evidence of good health. Access
33 24 to outside care and medical treatment are not matters for complaint or discussion.

37 25 Malaria is the most frequent disease in gold mining sites. When fever and influenza-like symptoms
38 26 occur, the miners self-diagnose, assume it is malaria and self-medicate to reduce seizures. In these
39 27 sites, the individual is responsible for their own disease management, the latter depending on what
40 28 medicine is available:

43 29 It's a bit risky yes; some people bring their medicines with them; they have malaria drugs
44 30 because there's a lot of malaria there. Sometimes people come with some anti-inflammatory
45 31 drugs. There's also other people who work selling medicines, all kinds of medicines. There's
46 32 no professional, no doctor there. *Rosa, mid 40's, female, manicurist, former gold miner*

49 33 Medications and condoms are bought in gold, and prices fluctuate. This constitutes a heavy financial
50 34 burden for the workers, effectively creating a barrier to disease prevention.

52 35 When the symptoms do not pass, the gold diggers leave the camp to seek treatment, often when their
53 36 health has already greatly deteriorated. For very serious cases, this is often difficult as the distance
54 37 to the closest healthcare structure is long. Often, it is necessary to take a canoe, which further delays
55 38 treatment, consequently lengthening the time spent self-medicating. Travel to hospitals only takes
56 39 place "*em caso da vida o morte*" ('when it's a matter of life or death'), as one participant, Rosa, put
57 40 it.

1
2 1 When study participants described the HIV symptoms they experienced, they often mentioned energy
3 2 loss, weight loss, fever, diarrhoea, and chills. These symptoms can be mistaken for signs of other
4 3 types of pathologies, such as malaria or dengue fever.

6 4 I'd already heard about it [HIV] before but I'd no idea what the symptoms were. If I'd known
7 5 those were the symptoms, I'd have gone earlier; I'd have gone to a doctor sooner, but because
8 6 I didn't know, I kept taking medicines for one thing or another... *Walter, mid 40s, male, pruner,*
9 7 *former gold miner*

12 8 Gold miners apply the general belief that humans hide both the fact that they are mortal and the
13 9 fundamental worry that comes with this; they live their lives as if the present will last forever (37).
14 10 Illness, including HIV seropositivity, can jeopardise the possibility to continue their gold-extraction
15 11 work:

18 12 Because when I got sick, I came here [to Oiapoque]; everything was there [the *Garimpo*], I
19 13 had to come back here. And I came here with what? With two backpacks and a child, and [I
20 14 am] still sick. It is what it is. *Rosa, mid 40s, female, manicurist, former gold miner*

23 15 Like the other study participants, HIV diagnosis was the main reason why Rosa stopped working in
24 16 the camp, and like them, she reported that she had a very difficult financial situation.

26 17 In addition to social backgrounds and working conditions, the importance of having a functional body
27 18 is shaped by gender roles and the construction of masculinity. Other types of structural relationships
28 19 determine *garimpeiros'* relationships to health and to illness, including poor access to health services,
29 20 repression of the camps by the French armed forces, threats of expulsion, and other administrative
30 21 difficulties.

33 22 **Circumstances of HIV diagnosis**

35 23 Three different circumstances for HIV diagnosis were identified in our study patients: opportunistic
36 24 disease, pregnancy, and having an HIV-positive partner. Gender influenced not only the circumstance
37 25 of their discovery of their positive HIV status, but also their approach to seeking healthcare.

40 26 *Opportunistic disease*

42 27 The three male *garimpeiros* discovered they were HIV positive because long-term symptoms led
43 28 them to be hospitalized. Walter was sick for three months at the *garimpo*, and went to look for care
44 29 because his fever did not go away:

46 30 When I went to St. Laurent, I did all kinds of tests, and nothing, nothing [no positive
47 31 test results]. When a nurse asked me if I wanted to be tested for HIV, I said "Do it!".
48 32 *Walter, mid 40s, male, pruner, former gold miner*

51 33 Sizhino was also diagnosed with HIV after seeking treatment for a fever. In both cases, the medical
52 34 staff did not immediately perform a HIV test. Only later, when the other test results proved
53 35 inconclusive, did they propose this test, and in an apologetic fashion. "Don't take this the wrong way"
54 36 the nurse said to Sizinho when inviting him to do the test. This illustrates how medical care providers
55 37 in this context may still see heterosexual men as a non-risk category for HIV.

58 38 Despite discovering his wife was HIV positive during her pregnancy, Anderson never wanted to get
59 39 tested. He finally went to the hospital to get medical care when he was already in a serious condition.
60 40 Like Aline's husband, Anderson did not want to believe that his wife was infected:

1
2 1 What made me not believe [that my wife was HIV positive], it's because I believe - honestly
3 2 - that I wanted to continue not believing, that is to say, because I didn't want treatment. I was
4 3 traumatized by doctors you see. I didn't like doctors because I thought doctors were doing
5 4 things to us, like to lab rats, right? *Laughter*. I didn't like it, so I didn't want to know. I thought
6 5 that through the faith I had in God, I could heal myself, if possible, I believed that. *Anderson,*
7 6 *mid 30s, male, bricklayer, former gold miner*

10
11 7 For these three participants, in addition to the mine being located far from any medical facility, having
12 8 doubts about their infection, the very existence of the disease (Anderson), and a confrontational
13 9 relationship with doctors, were all factors which prevented them from getting tested despite knowing
14 10 that their wives were HIV positive.

17 11 *HIV-positive partners and pregnancy*

20 12 Teresa was previously a cook in different *garimpos*. While she was resting at her family's house in
21 13 Oiapoque, she received a call from the regional hospital in French Guiana. Her companion, a gold
22 14 miner, had been hospitalised for a serious condition linked to an opportunistic disease. When she
23 15 arrived at his bedside, she was invited to have a HIV test. Only then did she discover she was
24 16 seropositive.

27 17 Rosa and Aline received their HIV positive result during prenatal care. They indicated that this was
28 18 very destabilizing for them as future mothers. Pregnant women have more frequent in contact with
29 19 medical institutions and our study highlights that women seem to be more likely to take up an offer
30 20 to have a test and to receive care. For our participants, discovering their seropositivity, whether during
31 21 routine check-ups (e.g., pregnancy) or during hospitalization for opportunistic diseases, was
32 22 unexpected as none thought they could be infected by HIV.

38 24 **DISCUSSION**

40 25 For many socially deprived people living along the French Guiana-Brazil border, the illegal gold
41 26 mining industry in the deep Amazonian forests of French Guiana represents one way to improve their
42 27 living standards. However, living conditions (months spent in remote sites, the threat of repression
43 28 (23)), and the social organisation of the *garimpos* (including paid sexual services, self-diagnosis and
44 29 self-medication) increase the likelihood of HIV infection in this population. Furthermore, access to
45 30 HIV testing is difficult (38). Our results suggest that even when the *garimpeiros* return to a supply
46 31 base, they do not take advantage of free HIV testing, as they do not perceive they are at risk, and
47 32 prefer to forget about possible at-risk behaviours they practice during their time in the *garimpo*.

52 33 In the *garimpo*, gender roles determine the functions allocated to each person. Mining activities are
53 34 associated with a specific construction of masculinity. This has been described in multiple settings
54 35 (39, 40, 41, 42) Masculinity is valorised through a specific relationship combining risk, alcohol and
55 36 sexuality. The activity of mining creates a specific organization of sexuality where geographical
56 37 distances influence conjugality. Women's sexuality can be a currency for exchange (43), and intimate
57 38 relationships a strategy for safety. The risk of HIV infection is managed through social identity (44-
58 39 46). It is most likely that the women in our study were infected during their stable relationship, as
59 40 this has been reported in other contexts where female non-sex workers had the highest HIV

1
2 1 prevalence in informal small-scale gold mines (47). Despite the fact that advances in treatment have
3 2 transformed HIV into a controlled chronic disease, being diagnosed represented a clear biographical
4 3 disruption (48) for the *ex-garimpeiros* interviewed.

6
7 4 The extraction of gold requires physical strength and endurance, which produces a particular
8 5 relationship with the body. Although *garimpeiros* arrive at the mining sites in a healthy condition,
9 6 the harsh working conditions there negatively impact their health (29). Representations of the self,
10 7 health and body, all play an important role in the decision to seek (or not) medical care (49). Disease
11 8 diagnosis and treatment depend on several factors including the geographic location of the camps.
12 9 *Garimpeiros* often self-medicate, sometimes for long periods (50). When they consult a doctor, it is
13 10 only for serious issues, often requiring hospitalization (51). It seems that *garimpeiros* do have access
14 11 to care when they seek it. The decision to be tested for HIV, whether it is provider initiated or self-
15 12 initiated, is important from both a personal and structural point of view. Compared to mainland France,
16 13 the capacity of the health system in French Guiana is limited. Internal territorial disparities,
17 14 discrimination, material and legal issues all contribute to build structural barriers to prevention and
18 15 healthcare access (52).

23
24 16 In the present study, the participants said that they were surprised when they tested HIV positive (44).
25 17 None had ever thought of spontaneously doing a test. Not frequently seeking healthcare (53), mistrust
26 18 of the medical profession, and not perceiving risks, can all lead to late HIV diagnosis. The latter can
27 19 also occur when medical staff do not consider heterosexual patients to be an at-risk population
28 20 (54,55), or when they are afraid to bring up the question of HIV during visits, considering it a sensitive
29 21 issue (56). In our study, what emerges from the doctors and the majority of the patients, is that most
30 22 of the people invited to test for HIV agreed to do so. It would appear that preparing the person for a
31 23 potential positive HIV diagnosis by first clearly explaining the disease, the test, and current
32 24 treatments, is fundamental, especially for pregnant women.

33
34 25 Using a comprehensive approach, this study shows the overlapping of structural, individual and
35 26 group-based factors in relation to HIV infection and its diagnosis, and provides a gendered
36 27 perspective of the target population's delay in seeking healthcare-seeking (57). Furthermore, it
37 28 validates the impact of illegal gold mining on this delay, and on health issues in general. Indeed, in a
38 29 context where research on health issues in general in French Guiana is scarce, this study is the first
39 30 in over twenty years to use an ethnographic approach to investigate people living with HIV (PLVIH)
40 31 in the French Amazon from a cross-border perspective (49).

41
42 32 Repressive policies applied to those on the margins of society in French Guiana create a situation
43 33 where seeking healthcare becomes difficult. *Garimpeiros'* attitudes towards health and HIV need to
44 34 be understood in a context where vulnerability to infection could jeopardize their livelihood.
45 35 Advocating a global not pathology-driven approach to healthcare is essential for this particularly
46 36 vulnerable population. Actions to fight HIV have been implemented over the last few years,
47 37 particularly at the border area with Brazil. The ongoing *Oyapock Coopération Santé* project has
48 38 increased the number of tests offered and bettered the access to ARV treatment at a transnational
49 39 level (35). This community-based approach by health mediators, who are familiar with the issues
50 40 involved, reinforces these efforts and enables gold miners to access these services when they leave
51 41 the *garimpo*.

1
2 1 Ongoing studies on malaria (Malakit) (30) show that when tests are offered on site, or combined with
3 2 other services, people readily agree to them. Continued efforts to provide access to health and
4 3 prevention, and to integrate HIV testing into routine check-ups could reduce the time between
5 4 infection and diagnosis and help to reduce the HIV epidemic. Similar actions have already borne fruit
6 5 elsewhere (30,35), and should be scaled-up and funded over the long term. Furthermore, providing
7 6 free HIV testing, self-tests and pre-exposure prophylaxis directly in camps could also be beneficial.
8 7 Outreach focusing on educating *garimpeiros* and their partners on health and safety, especially
9 8 regarding HIV symptoms and prevention, could promote community empowerment on health issues.
10 9 This was an exploratory study. In-depth studies are needed to better understand the determinants of
11 10 delayed testing and treating of this migrant population which is at particular risk of HIV infection.

12 11 One limitation of our study is that the fieldwork could not be performed directly with current miners
13 12 in illegal camps, due to their geographical inaccessibility to researchers and logistical constraints.
14 13 However, the experiences of former miners and other persons previously connected to this industry
15 14 in French Guiana means that this survey - the first of its kind - brings to light health determinants
16 15 which are specific to gold workers in the country. A second limitation is potential selection bias, as
17 16 participants were recruited by medical and other healthcare staff. Furthermore, the study was
18 17 performed in Saint-Georges. It would have been interesting to include PLHIV living in other parts of
19 18 French Guiana.

20 19 **CONCLUSION**

21 20 Illegal gold mining in French Guiana involves the mobility of migrant Brazilian workers living in
22 21 social deprivation living in deep forest, experiencing repression by the French state and possible
23 22 eviction. These conditions generate a relationship with one's body, and negatively impact health and
24 23 healthcare-seeking behaviours. *Garimpeiros* perceive that less contact with doctors is evidence of
25 24 their good health. Social constructions of both gender - especially masculinity - and HIV risk
26 25 categories, still impact access to HIV testing, leading to poorer health and late HIV diagnosis. Taking
27 26 into account the specific difficulties *garimpeiros* face when proposing healthcare options for them,
28 27 including HIV screening mobile units would improve access to healthcare and overall health, and
29 28 would reduce the HIV burden in this vulnerable population.

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Patient consent: Oral non-opposition was obtained.

Ethics approval: This study was conducted in accordance with the French national public health code and in compliance with the General Data Protection Regulation (EU 2016/679), which is the strictest regulation in the world governing the protection of patients' rights and the use of health data. In accordance with French regulations, this study was conducted without the need for consent from an ethics committee. Moreover, it was conducted according to the principle of the reference methodologies of France's National Commission on Informatics and Liberty (CNIL). A privacy impact study was also conducted.

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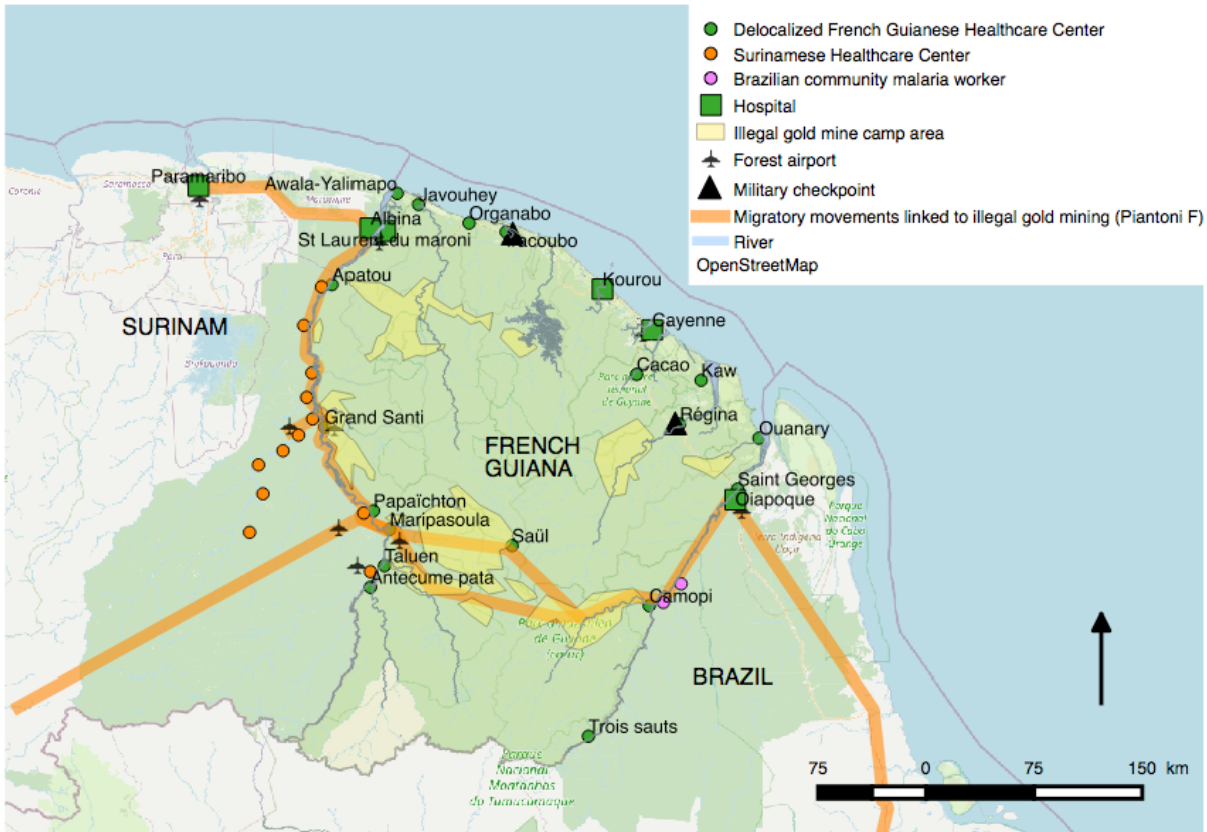
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40 **Figure 1.** Map of healthcare centers, gold mine area and migratory movements linked to illegal gold
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42 using QGIS Geographic Information System. Open Source Geospatial Foundation Project.
43 <http://qgis.osgeo.org>
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Standards for Reporting Qualitative Research (SRQR)*

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Page/line no(s).

Title and abstract

<p>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</p>	<p>Done, Page:1 Line:2</p>
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	<p>Done, Page:2 Line:1</p>

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	<p>Done, Page: 3 and 4</p>
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	<p>Done Page:4 Line:17</p>

Methods

<p>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**</p>	<p>Done Page: 4 Line: 31 Page 5 Line:11-14</p>
<p>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</p>	<p>Done Page: 5 Line: 24</p>
<p>Context - Setting/site and salient contextual factors; rationale**</p>	<p>Done Page 4 Line 31- 41</p>
<p>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**</p>	<p>Done, Page:4 Line:36</p>
<p>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</p>	<p>Done Page:5 Line: 1 to 5</p>
<p>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**</p>	<p>Done method section</p>

1 2 3 4 5	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	Done Page:5 Line: 20
6 7 8	Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Done Page: 5 Line: 36
9 10 11 12	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	Done Page:5 Line: 11
13 14 15 16	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**	Done Page: 5 Line: 21-24
17 18 19 20	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Done Page: 5 Line: 22

Results/findings

23 24 25 26	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	Done, ` results section P7-P11
27 28 29	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Done, results section

Discussion

32 33 34 35 36 37	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	Done, discussion section P11-12
38 39	Limitations - Trustworthiness and limitations of findings	Done, Page: 12 Line:12 to18

Other

42 43 44	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Done Page: 12 Line: 16
45 46	Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Done

*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.

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**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
DOI: 10.1097/ACM.0000000000000388

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TITLE:**What can lead to late diagnosis of HIV in an illegal gold mining environment? A qualitative study at the French Guiana border with Brazil.**

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French Guiana, HIV, goldmines, late diagnosis, gender, Amazonia, undocumented immigrants, access to healthcare

1 2 1 **ABSTRACT**

3 4 2 **Objective:**

5 3 The present study aimed to understand what factors can lead to late HIV diagnosis of illegal gold
6 4 miners at French Guiana's border with Brazil.

7 5 8 6 **Design:**

9 7 An exploratory qualitative study with in-depth interviews and observations was conducted between
10 8 November 2019 and February 2020.

11 9 12 10 **Setting:**

13 11 The study was conducted in the main medical healthcare service and two Non-Governmental
14 12 Organisations' (NGO) premises in the Oyapock border region, which is a supply area for illegal gold
15 13 mining sites.

16 14 17 15 **Participants:**

18 16 Fifteen people living with HIV diagnosed with a CD4 count under 350/mm³ were interviewed. Seven
19 17 women and eight men participated; they were between 31 and 79 years old, and the median time since
20 18 HIV diagnosis was six years. Eight had links to illegal gold mining.

21 19 22 20 **Findings:**

23 21 Three key themes for late HIV diagnosis emerged: 1) The presence of economic and political
24 22 structural factors which constitute risks for this illegal activity, specifically, the repression of gold
25 23 mining sites by French armed forces and the distance from healthcare facilities; 2) Representations
26 24 of the body and of health, related to the living conditions of this population; prioritization of health
27 25 emergencies and long-term self-medication; 3) Gender roles shaping masculinity and heterosexuality
28 26 contributing to a perception of not being at risk of HIV and delaying testing.

29 27 30 28 **Conclusion**

31 29 This study highlights structural, group-based and individual factors that reduce access to HIV testing
32 30 and healthcare in general for a population of migrant workers in an illegal gold-mining area. Faced
33 31 with harsh living conditions and state repression, these workers develop a vision of health which
34 32 prioritizes the functionality of the body. Associated with gender roles which are partly shaped both
35 33 by the mining activity and its geographic location, this vision can lead to late HIV diagnosis.

36 34 37 35 **Study strengths and limitations**

38 36 *Strengths*

- 39 37 • This is the first qualitative study on late diagnosis of HIV in illegal gold miners in
40 38 Amazonia at the French Guiana-Brazil border
- 41 39 • It documents a specific HIV context with few existing data
- 42 40 • The study shows how structural, individual and group-based factors overlap to lead to late
43 41 HIV diagnosis.
- 44 42 • An anthropological approach was used to study representations of health and HIV in the
45 43 goldminer population.

46 44 *Limitations*

- 47 45 • Study participants were not directly observed/interviews at goldmining camps.

1 2 1 MAIN TEXT:

3 4 2 INTRODUCTION

5
6 3 French Guiana is the region of France most impacted by Human Immunodeficiency Virus (HIV) with
7 4 a prevalence of 1.25% in the general population (1). Located in continental America, it is 7 000 km
8 5 from Paris. The Amazonian forest represents 97% of its territory. The ethnical background of the
9 6 region's approximately 270 000 (2) inhabitants reflect its colonial history: Creoles, indigenous
10 7 peoples, Bushinengue, persons from mainland France, as well as recent immigrants seeking a better
11 8 life, mostly from Surinam, Brazil and Haiti (3). The presence of the French State in this area is mainly
12 9 visible through the school system, the health system and the presence of the army, which carries out
13 10 training and operations (4). Compared with mainland France, the health system is under-resourced,
14 11 with inequalities between the coastal and inland areas. (5,6)

15 12 With one of the highest unemployment rates in France, and a large number of people living below
16 13 the poverty line, social inequalities accumulate in French Guiana, facilitating the spread of HIV (5).
17 14 It has been shown that social, economic, racial and gender inequalities make people more vulnerable
18 15 to HIV. Daily difficulties with housing, food, transport, and immigration status all impact both
19 16 condom negotiation and access to prevention and care (7).

20 17 The HIV epidemic particularly affects migrant populations (8,9). Contrary to the claims by some that
21 18 HIV positive migrants are already infected when they arrive, it would appear that most become
22 19 infected after their arrival (9,10). Despite both France and Brazil having HIV 'test and treat' policies,
23 20 access to healthcare in the isolated Amazonian areas of French Guiana is impacted by territorial
24 21 inequalities, and the epidemic continues to grow there (e.g., incidence in 2010-2015 increased from
25 22 32.09 to 42.35 per 10,000) (6). Among Brazilian immigrants, HIV diagnosis occurs approximately
26 23 3.7 years later than in other population groups (11). HIV incidence is also increasing in the
27 24 neighbouring Brazilian state of Amapá (+21,2% in 2009-2019) (12).

28 25 The border between the two countries represents a typical marginalised border area (13) with
29 26 asymmetric wealth, poor living conditions, little access to education, temporary population mobility
30 27 and a flourishing sex trade which is often linked to nearby illegal gold mining in French Guiana
31 28 (14,15). Geographically distant from decision-making centres, this area remains economically and
32 29 politically neglected by both France and Brazil (16-18).

33 30 The border towns Saint-Georges (French Guiana, approximately 5 000 inhabitants) and Oiapoque
34 31 (Brazil, approximately 25 000 inhabitants) are located on opposite sides of the Oyapock river.
35 32 Oiapoque is a support base for the illegal gold mining industry located deep in the forests of French
36 33 Guiana. It is a primary point of arrival and departure for Brazilian gold miners. Populations here are
37 34 very exposed to health vulnerability (19,20), HIV treatment being available in Oiapoque only since
38 35 2019.

39 36 Approximately 10 000 gold miners work in the estimated 600 gold mining sites in French Guiana
40 37 (21). The region has mostly small- and medium-scale artisanal mining operations, the majority of
41 38 which are illegal (called *garimpos*), with workforces comprising mainly Brazilian miners (called
42 39 *garimpeiros*) (22–25). The social organisation of the *garimpo* is governed by norms, constraints and
43 40 sanctions that exist outside of state mediation (26). The *garimpeiros* associate with *donos* (bosses)

1 through very detailed oral contracts that formalise the work and the type of remuneration, mainly by
2 1 percentage (23,26). Beside work-based hazards, the *garimpos* are subject to campaigns to eradicate
3 2 illegal gold mining by the ongoing French military operation Harpie (27). These campaigns
4 3 accentuate the temporary and improvised nature this activity.
5 4

6 5 The complex socio-political contexts of illegal mining camps means that they are hard to document
7 6 from a scientific perspective as physical access is difficult for researchers (23,28). In the limited
8 7 literature available on French Guiana, medical surveys found that gold miners' working and living
9 8 conditions led to poor health, a high prevalence of infectious and non-infectious diseases including
10 9 HIV, and limited access to healthcare (29,30). In 2013, primary healthcare centres located on French
11 10 Guiana's border with Brazil observed an increase in HIV seropositivity. Brazilian patients involved
12 11 in gold mining were the most exposed. A third of the cases were diagnosed late (i.e., defined as a
13 12 CD4 count < 350 cells / mm³) (31). Understanding the reasons for late HIV diagnosis in this socially
14 13 deprived migratory population who know little about HIV testing or prevention tools (14,32,33) is
15 14 essential to improve healthcare.

16 15 In this peripheral multilingual geographic context, using an exploratory anthropological research
17 16 approach, the present study aimed to bring new evidence to the currently scarce data on factors
18 17 leading to late HIV diagnosis. More specifically, it aimed to study how structural, individual and
19 18 group-based social constructions can lead to late HIV diagnosis by gathering and analysing data on
20 19 the experiences of patients living with HIV who are diagnosed late.
21 20

22 21 **METHODS**

23 22 **Patient and Public Involvement statement:**

24 23 No person living with HIV (PLHIV) was directly involved in the design of the study. The original
25 24 research question emerged from physicians working in the border region. The interview guide and
26 25 data collection methods were revised and validated by community health workers involved in PLHIV
27 26 medical follow-up. We had planned to present the results to participants but this was delayed because
28 27 of the COVID-19 border restrictions.
29 28

30 29 **Study design:**

31 30 Between November 2019 and February 2020, an ethnographic anthropological research study was
32 31 conducted combining observations in a medical healthcare service and two Non-Governmental
33 32 Organisations' (NGO) premises with in-depth individual interviews at the border area between
34 33 French Guiana and Brazil (Figure 1).
35 34

36 35 **Data collection:**

37 36 Of the 55 PLHIV who frequented the primary health centre for follow-up at least once in the year
38 37 preceding the study period, a panel of 21 patients with late diagnosis was identified by the referring
39 38 infectious diseases physician. Late HIV diagnosis was defined as a CD4 count below 350mm³ at
40 39 diagnosis. The maximum time between diagnosis and study inclusion was 21 years, with a median of
41 40 six years. Patients were then contacted by the healthcare mediator in charge of their medical follow-
42 41 up. Study participation was proposed during medical consultation or by phone. Fifteen of the 21
43 42 patients agreed to participate and constituted the study sample. Of these, eight had either formerly
44 43

1 worked in illegal gold mines in French Guiana and/or elsewhere or were/had been married to a gold
2 miner. Before the interview and before written consent was obtained, the study was explained to the
3 participants, and patient confidentiality and data privacy issues were clarified. The ethical
4 permissions granted by the Cayenne Hospital's ethical committee (UF6000/27.b) and the French
5 National Commission on Informatics and Liberties (# 2215827) allowed us to retrieve specific data
6 (CD4 count at diagnosis and low CD4 Nadir) - with patients' consent - from their medical records.

7 Interviews lasted between 60 and 90 minutes. They were conducted in French (n=2) and/or
8 Portuguese (n=13) and translated simultaneously into French by a HIV community health mediator.
9 The following themes were discussed during the interviews: life and migration trajectory, experience
10 of gold mining, HIV risk perceptions, HIV screening and diagnosis history, seeking care and
11 treatment, social life and everyday experience with HIV. In addition, ethnographic observations of
12 both medical consultations and NGO HIV prevention activities were performed. An inductive method
13 was used for both study dimensions, whereby the interview and observation guides could be adapted
14 to new themes that emerged during data collection, and whereby initial protocol-defined data
15 collection and categorisation techniques could be modified (34).

16 The study was implemented in collaboration with *Oyapock coopération santé*, a French-Brazilian
17 project to improve access to HIV care and sexual health at the border between the two countries (35).

18 **Analysis:**

19 Audio recordings of interviews and notes taken during observations were transcribed, coded manually
20 and anonymized. The exploration and production of various sources (interviews, observations and
21 written materials) enabled us to triangulate the data (36). Transcript analysis was performed following
22 thematic classification. This made it possible to identify specific sub-themes through occurrences and
23 recurrences and analysis of correlations. The analysis focused on data in both French and Portuguese.
24 The linguistic skills in Portuguese acquired by the interviewer/researcher during fieldwork enabled
25 her to subsequently make a transversal analysis of the material collected.

26 **Ethics:** Biological results were retrieved anonymously from computerized medical charts. The
27 retrospective use of anonymous patient files located in patient care services was authorized by the
28 Cayenne Hospital's ethical committee (UF6000/27.b) and the French National Commission on
29 Informatics and Liberties (# 2215827). All the data collected retrospectively were anonymized in a
30 standardized case report form. Both ethics approval and consent from the participants were obtained
31 for the interviews (see below).

32 **RESULTS**

33 **Participants' characteristics:**

34 Seven women and eight men living with HIV participated, aged between 31 and 79 years old (Table
35 1). One of the 15 self-defined as homosexual. During the analysis of sharing experienced and
36 trajectories, a goldminer-related subgroup clearly emerged. Three men and three women were former
37 workers in the gold mines while two women had never worked in the industry but were/had been
38 married to a miner. The present analysis focuses on these 8 people. The heterogeneity of the rest of
39 the participants prevented us from being able to make a comparison with persons connected to gold-
40 mining and those who were not.

1
2 1 Nine topics emerged from the analysis of the individual interviews and observations. (Table 2).

3
4 2 **Table 1.** Summary of study participants' characteristics (N=15)

	Pseudonym	Sex	Age range	Number of Years diagnosed HIV positive	CD4+* count at diagnosis	Low CD4+* nadir	Goldmining-related activity
1	Aline	F	late 30s	3	302	104	Married to a gold-miner
2	Anderson	M	late 30s	6	15	15	Former gold-miner
3	André	M	mid 40s	1			no
4	Felipe	M	early 40s	4	200	199	no
5	Ana	F	early 40s	4	233	233	Former gold-miner
							Married to a gold-miner
6	Janaina	F	early 60s	5	136	136	no
7	João	M	mid 40s	6	281	105	no
8	Julia	F	mid 40s	6	56	56	no
					<350 (Amapá, BR)	<350 (Amapá, BR)	no
9	Juliano	M	early 30s	11	Unknown at diagnosis	Unknown at diagnosis	no
10	Oscar	M	mid 40s	21	Unknown at diagnosis	Unknown at diagnosis	no
11	Patricia	F	late 40s	5	196	196	no
					Unknown at diagnosis	Unknown at diagnosis	Former gold-miner
12	Rosa	F	mid 40s	6	103	103	Former gold-miner
13	Sizinho	M	late 70s	9	103	103	Former gold-miner
					<350 (Amapá, BR)	<350 (Amapá, BR)	Former gold-miner
14	Teresa	F	mid 40s	7	164	164	Former gold-miner
15	Walter	M	mid 40s	5	164	164	Former gold-miner

35 3 *CD4+ in cells/mm³

36 4

37 5

38 6 **Table 2.** Main topics discussed during interviews with HIV-positive patients

39 7

Topics

Life Trajectory (childhood, professional activity, migration)

Goldmines, access to healthcare at gold-mine sites

Context of HIV diagnosis (pregnancy, HIV-positive partner, opportunistic disease)

Access to healthcare (HIV and other) in Brazil and French Guiana

Pre-diagnosis representations and knowledge of HIV

Sexuality (sex life, conjugality, gender role)

Representation of Body and of Health

Experience of living with HIV (Acceptance, discrimination, status disclosure)

Police and administrative problems

54 8

55
56 9 **Illegal small-scale gold mining: a specific context**

57
58 10 Illegal small-scale gold mining in French Guiana involves migration from poor regions of north and
59 11 northeast Brazil and mobility from mining camps to support bases. Oiapoque, where most of the
60 12 participants lived at the time of this study, is one such base. According to the HIV community health

mediator: “Oiapoque in its entirety was built with gold”. Despite the destruction of illegal gold mining camps in the forest by the French government (see operation Harpie above), Brazilian *garimpeiros* continue to build new ones. This is because compared with other types of jobs available in the Brazilian Amazon regions, illegal small-scale gold mining in French Guiana provides the *garimpeiros* with a lot of freedom (choice of employer, of informal contract, etc.) and the chance to make more money. This explains why, despite the dangerousness of the work, the hazards of production, and repressive policies, gold mining still attracts many people in search for a better life.

I thought that there was the possibility of earning more money there; everyone was talking about it. I went through that experience, I ‘went in’ and I worked there. *Anderson, late 30s, male, bricklayer, former gold miner*

In remote areas of the Amazon rainforest, gold mining camps form micro-societies for places of work, social and economic exchange, and daily life. Because of the setting of the activity, working in an illegal mine (*garimpo* in Portuguese) involves a time commitment from several months to years.

When I went, I didn’t get out. I did go out [for short periods] around 10 times because I stayed there for such a long time: 10 years. *Sizinho, late 70s, male, former gold miner*

The six *garimpeiros* interviewed had experienced government-based repression in their mining camps; some were arrested and then released. The complete destruction of a gold mining camp is the most common technique used by the police and the French army. For the *garimpeiros*, this means fleeing into the forest for several days, with the consequent risks (getting lost, no water, etc.).

When they arrive, you run; if you have time you untie your hammock, if you don't, you leave everything behind and run; you save your skin. *Walter, mid 40s, male, tree pruner, former gold miner*

The long periods of stay in the forest, moving in and out of the sites, and facing camp destruction all represent a specific lifestyle with its own temporality. The socioeconomic environment in these sites, their geographical isolation, and the illegality of the working practices all accentuate problems accessing HIV prevention/testing tools and services as well as treatment.

Gender roles, emotional and sexual relationships at the *garimpo*

The gold mining industry - whether practiced legally or not - impacts gender roles, sexuality and conjugality. More specifically, the work environment and geographical distance from their homes affects *garimpeiros*’ sexual life, not only in the camps but also when they go back to their families in Brazil. Gender roles also shape relationships in the camps. The construction of masculinity around virility is justified by the physically demanding work of extraction.

With regard to prostitution, Sizinho (*79, male, late 70s, former gold miner*) said:

There are many of them; at night there are the brothels that are open; it’s a woman’s work. You drink, you dance and do your business [...] We spent a lot too: alcohol, partying, women, all night, all night, all night long.

In addition to promoting virility, the physical and dangerous element of the work shapes relationships with self-risk. Compared with the daily risks of mining and repression, miners put the less visible risks into perspective, such as HIV contamination. Most of the men interviewed, whether married or

1
2 1 not, came on their own to the gold mining camps and saw their families between once a month and
3 2 once a year. This has an impact on sexuality, as men develop several types of relationships including
4 3 paying for sexual services and 'second home' type relationships.

6 4 Despite the very masculine environment - *garimpeiros* are almost exclusively men - women are also
7 5 present in the camps. They mostly work as cooks and sex workers; some own gold-extraction
8 6 machines. Their roles and the types of work they do also have gender-specific constraints. Three of
9 7 the women in this study were involved directly in the gold economy.

12 8 Some women go there to work in the kitchen; some women go there to work in prostitution.
13 9 There are women who aren't prostitutes, who don't go to work in prostitution, but on the other
14 10 hand they can pay for a lift [by canoe] by prostituting themselves. Everyone does business
15 11 with the person that suits them. It's very, very dangerous for a woman there, but once you've
16 12 made acquaintances, once you see who can help you, who's strong, who can defend you, you
17 13 do business with that person. *Rosa, mid 40s, female, manicurist, former gold-miner*

21 14 In the case of women who come to the *garimpo* alone, developing intimate relationships within the
22 15 camp is a strategy for survival. Apart from prostitution, sexuality is a way to obtain services (e.g.,
23 16 ride to the nearest town), and represents a protection strategy in an environment regulated by the
24 17 threat of violence.

27 18 In terms of risk prevention, although wearing a condom can quite easily be negotiated in transactional
28 19 sex, this becomes more difficult when sexuality is part of an intimate relationship. Couples at the
29 20 camps are formed and are related to the context, For example, Walter had "*uma namorada*", a
30 21 girlfriend, in the camp where he had spent the most time; Rosa and Anderson met each other in a
31 22 camp. Couples created in camps can exist in parallel with and/or in competition with marital
32 23 relationships. Janaina discovered that her husband had an affair in the *garimpo* and this led to their
33 24 separation. During their marriage, the couple had not used any form of contraception:

37 25 No, I wasn't using anything; I also thought he wasn't with anyone there; it was a marriage,
38 26 wasn't it? *Janaina, early 60s, female, farmer*

40 27 Outside the *garimpo*, heterosexual couples - where power relations are unequal and for which social
41 28 expectations on fidelity are strong - therefore constitute a context for disease transmission. When a
42 29 married man comes home from the *garimpo*, the monogamous contract, together with economic and
43 30 emotional dependence, means hoping that the other person (whether the husband or wife) has been
44 31 faithful during the absence. This leads to a perception of being safe from potential sexually
45 32 transmissible infections.

51 34 **Having a functional body: perceiving health as the absence of symptoms**

52 35 Brazilians who migrate to the illegal gold mines in French Guiana in search of a better life are often
53 36 uneducated. However, they have other types of knowledge and skills. As gold mining requires
54 37 physical strength and endurance, health and illness are fundamental issues. *Garimpeiros* perceive that
55 38 being in good health is mainly related to the proper functioning of the body. They fear disabling
56 39 illnesses most and tend to minimize the importance of aches and pains. In our study, "*Tudo bem*"
57 40 ('everything's fine' in Portuguese), was the most common answer to questions about health during

1
2 1 the interviews. For *garimpeiros*, less contact with doctors is greater evidence of good health. Access
3 2 to outside care and medical treatment are not matters for complaint or discussion.

4
5 3 Malaria is the most frequent disease in gold mining sites. When fever and influenza-like symptoms
6 4 occur, the miners self-diagnose, assume it is malaria and self-medicate to reduce seizures. In gold
7 5 mining sites, the individual is responsible for their own disease management, the latter depending on
8 6 what medicine is available:

9
10
11 7 It's a bit risky yes; some people bring their medicines with them; they have malaria drugs
12 8 because there's a lot of malaria there. Sometimes people come with some anti-inflammatory
13 9 drugs; there's also other people who work selling medicines, all kinds of medicines. There's
14 10 no professional, no doctor there. *Rosa, mid 40's, female, manicurist, former gold miner*

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17 11 Medications and condoms are bought in gold, and prices fluctuate. This constitutes a heavy financial
18 12 burden for the workers, effectively creating a barrier to disease prevention.

19
20 13 When the symptoms do not pass, the gold diggers leave the camp to seek treatment, often when their
21 14 health has already greatly deteriorated. For very serious cases, this is often difficult as the distance
22 15 to the closest healthcare structure is long. Often, it is necessary to take a canoe, which further delays
23 16 treatment, consequently lengthening the time spent self-medicating. Travel to hospitals only takes
24 17 place "*em caso da vida o morte*" ('when it's a matter of life or death'), as one participant, Rosa, put
25 18 it.

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29 19 When study participants described the HIV symptoms they experienced, they often mentioned energy
30 20 loss, weight loss, fever, diarrhoea, and chills. These symptoms can be mistaken for signs of other
31 21 types of pathologies, such as malaria or dengue fever.

32
33 22 I'd already heard about it [HIV] before but I'd no idea what the symptoms were. If I'd known
34 23 those were the symptoms, I'd have gone earlier; I'd have gone to a doctor sooner, but because
35 24 I didn't know, I kept taking medicines for one thing or another... *Walter, mid 40s, male,*
36 25 *pruner, former gold miner*

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38
39 26 Gold miners apply the general belief that humans hide both the fact that they are mortal and the
40 27 fundamental worry that comes with this, and live their lives as if the present will last forever (37).
41 28 Illness, including HIV seropositivity, can jeopardise the possibility to continue their gold-extraction
42 29 work:

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45 30 Because when I got sick, I came here [Oiapoque]; everything was there [the *Garimpo*], I had
46 31 to come back here. And I came here with what? With two backpacks and a child, and still
47 32 sick. It is what it is. *Rosa, mid 40s, female, manicurist, former gold miner*

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50 33 Like the other study participants, HIV diagnosis was the main reason why Rosa stopped working in
51 34 the camp. Like them, her financial situation was very difficult when interviewed.

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53 35 Social backgrounds and working conditions influence goldminer's health seeking behaviours. Other
54 36 types of structural relationships also affect *garimpeiros'* relationships to health and to illness,
55 37 including poor access to health services, repression of the camps by the French armed forces, threats
56 38 of expulsion, and other administrative difficulties.

Circumstances of HIV diagnosis

Patients in our study discovered they were HIV positive in three different circumstances: opportunistic disease, during pregnancy, and having HIV-positive partner. Gender influenced not only the circumstance of their discovery of their positive HIV status, but also their approach to seeking healthcare.

Opportunistic disease

The three male *garimpeiros* discovered they were HIV positive because long-term symptoms led them to be hospitalized. Walter was sick for three months at the *garimpo*, and went to look for care because his fever did not go away:

When I went to St. Laurent, I did all kinds of tests, and nothing, nothing [no positive test results]. When a nurse asked me if I wanted to be tested for HIV, I said “Do it!”.

Walter, mid 40s, male, pruner, former gold miner

Sizhino was also diagnosed with HIV after seeking treatment for a fever. In both cases, the medical staff did not immediately perform a HIV test. Only later, when the other test results proved inconclusive, did they propose this test, and in an apologetic fashion. “Don’t take this the wrong way” the nurse said to Sizinho when inviting him to do the test. This illustrates how medical care providers in this context may still see heterosexual men as a non-risk category for HIV.

Despite discovering his wife was HIV positive during her pregnancy, Anderson never wanted to get tested. He finally went to the hospital to get medical care when he was already in a serious condition. Like Aline’s husband, Anderson did not want to believe that his wife was infected:

What made me not believe [that my wife was HIV positive], it’s because I believe - honestly - that I wanted to continue not believing, that is to say, because I didn’t want treatment. I was traumatized by doctors you see. I didn’t like doctors because I thought doctors were doing things to us, like to lab rats, right? *Laughter*. I didn’t like it, so I didn’t want to know. I thought that through the faith I had in God, I could heal myself, if possible, I believed that. *Anderson, mid 30s, male, bricklayer, former gold miner*

For these three participants, in addition to the mine being located far from any medical facility, having doubts about their infection, the very existence of the disease (Anderson), and a confrontational relationship with doctors, were all factors which prevented them from getting tested despite knowing that their wives were HIV positive.

HIV-positive partners and pregnancy

Teresa was previously a cook in different *garimpos*. While she was resting at her family’s house in Oiapoque, she received a call from the regional hospital in French Guiana. Her companion, a gold miner, had been hospitalised in a serious condition for an opportunistic disease. When she arrived at his bedside, she was invited to have a HIV test. Only then did she discover she was seropositive.

Rosa and Aline discovered they were HIV positive during prenatal care, and indicated that this was very destabilizing for them as future mothers. Pregnant women have more frequent in contact with medical institutions and our study highlights that women seem to be more likely to take up an offer to have a test and to receive care. For our participants, discovering their seropositivity, whether during

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2 1 routine check-ups (e.g., pregnancy) or during hospitalization for opportunistic diseases, was
3 2 unexpected as none thought they could be infected by HIV.
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7 4 **DISCUSSION**

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10 5 The illegal gold mining industry in the deep Amazonian forests of French Guiana represents one
11 6 means to finding a better life for many socially deprived people living along the French Guiana-Brazil
12 7 border. Living conditions (months spent on remote sites, the threat of repression (23)), and the social
13 8 organisation of the camps (paid sexual services, self-diagnosis and medication) increase the
14 9 likelihood of HIV infection in this population. Furthermore, access to HIV testing is difficult (38).
15 10 Our results suggest that even when the *garimpeiros* return to a supply area, they do not take advantage
16 11 of free HIV testing, as they do not perceive they are at risk, and prefer to forget about possible at-risk
17 12 behaviours they practice during their time in gold mine sites.
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21 13 At the *garimpo*, gender roles determine the functions allocated to each person. Masculinity is
22 14 valorised through a specific relationship combining risk, alcohol and sexuality (39,40). The mining
23 15 activity creates a specific organization of sexuality where geographical distances influence
24 16 conjugality. Women's sexuality can be a currency for exchange (41) and intimate relationships a
25 17 strategy for safety. The risk of HIV infection is managed through social identity (42-44). It is most
26 18 likely that the women in our study were infected during their stable relationship, as this has been
27 19 reported in other contexts where female non-sex workers had the highest HIV prevalence in informal
28 20 small-scale gold mines (45). Despite the fact that advances in treatment have transformed HIV into a
29 21 controlled chronic disease, being diagnosed with HIV represented a clear biographical disruption (46)
30 22 for the *ex-garimpeiros* interviewed.
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37 24 The physical extraction of gold requires physical strength and endurance, which produces a particular
38 25 relationship with the body. Although *garimpeiros* arrive at the mining sites in good health, the harsh
39 26 working conditions there negatively impact their health (29). Representations of the self, health and
40 27 body, all play an important role in the decision to seek (or not) medical care (47). Disease diagnosis
41 28 and treatment depend on several factors including the geographic location of the camps. *Garimpeiros*
42 29 often self-medicate, sometimes for long periods (48). When they consult a doctor, it is only for serious
43 30 issues, often requiring hospitalization (49).
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48 31 In the present study, the participants said that they were surprised when they tested HIV positive (42).
49 32 None had ever thought of spontaneously doing a test. Not frequently seeking healthcare (50), mistrust
50 33 of the medical profession, and not perceiving risks, can all lead to late HIV diagnosis. The latter can
51 34 also occur when medical staff do not consider heterosexual patients as an at-risk population (51,52).
52 35 In our study, what emerges from the doctors and the majority of the patients is that most of the people
53 36 invited to test agreed to do so. It would appear that preparing the person for a potential positive HIV
54 37 diagnosis by first clearly explaining the disease itself, the test, and current treatments is fundamental,
55 38 especially for pregnant women.
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59 39 Using a comprehensive approach, this study shows the overlapping of structural, individual and
60 40 group-based factors in relation to HIV infection and its diagnosis, and provides a gendered

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2 1 perspective of the target population's delay in seeking healthcare-seeking (53). Furthermore, it
3 2 validates the impact of illegal gold mining on this delay and on health issues in general. Indeed, in a
4 3 context where research on health issues in French Guiana is scarce, this study is the first in over
5 4 twenty years to use an ethnographic approach to investigate people living with HIV (PLVIH) in the
6 5 French Amazon from a cross-border perspective (47).

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9 6 One limitation of our study is that the field work could not be performed directly with current miners
10 7 at the illegal camps, due to their inaccessibility to researchers for obvious reasons. However, the
11 8 experiences of former miners and other persons previously connected to this industry in French
12 9 Guiana, means that this survey - the first of its kind - provides excellent evidence for the situation of
13 10 gold workers there. A second limitation is potential selection bias, as participants were recruited by
14 11 medical and other healthcare staff. Furthermore, it would have been interesting to include PLHIV
15 12 living in other parts of the French Guyanese territory.

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19 13 Repressive policies applied to those on the margins of society in French Guiana create a situation
20 14 where seeking healthcare becomes difficult. *Garimpeiros'* attitudes towards health and HIV need to
21 15 be understood in a context where vulnerability to infection could jeopardize their livelihood.
22 16 Advocating for a global not pathology-driven approach to healthcare is essential for this particularly
23 17 vulnerable population. Actions to fight HIV have been implemented over the last few years,
24 18 particularly at the Guiana-Brazil border area. The *Oyapock Coopération Santé* project increased the
25 19 number of tests offered and bettered the access to ARV treatment at a transnational level (35). This
26 20 community-based approach by health-mediators who are familiar with the issues involved, reinforces
27 21 these efforts and enables gold miners to access these services when they leave the *garimpo*.

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32 22 Ongoing studies, particularly on malaria (Malakit) (30), show that when tests are offered on site, or
33 23 combined with other services, people readily agree to them. Continued efforts to provide access to
34 24 health and prevention, and to integrate HIV into routine check-ups could reduce the time between
35 25 infection and diagnosis and help to reduce the HIV epidemic. These actions, which have already
36 26 borne fruit (30,35), should be perpetuated and funded in the long term. Furthermore, providing free
37 27 HIV testing, self-tests and pre-exposure prophylaxis directly in camps could also be beneficial.
38 28 Outreach focusing on educating *garimpeiros* and their partners on health and safety, especially
39 29 regarding HIV symptoms and prevention, could promote community empowerment on health issues.
40 30 This study is exploratory. In-depth studies are needed to better understand the determinants of delayed
41 31 in testing and treating this migrant population, which is at particular risk of HIV infection.

42 43 44 45 46 47 48 49 33 **CONCLUSION**

50 34 Illegal gold mining in French Guiana involves the mobility of migrant Brazilian workers living in
51 35 social deprivation living in deep forest, experiencing repression by the French state and possible
52 36 eviction. These conditions generate a relationship to the body and negatively impact health and
53 37 healthcare-seeking behaviours. *Garimpeiros* perceive that less contact with doctors is evidence of
54 38 their good health. Social constructions of both gender - especially masculinity - and HIV risk
55 39 categories, still impact access to HIV testing, leading to deteriorating health and late HIV diagnosis.
56 40 Taking into account the specific difficulties *garimpeiros* face when proposing healthcare options for
57 41 them, including HIV screening mobile units, would improve access to healthcare and overall health,
58 42 and would reduce the HIV burden in this vulnerable population.

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Competing interests: The authors declare that they have no competing interests.

Patient consent: Oral non-opposition was obtained.

Ethics approval: This study was conducted in accordance with the French national public health code and in compliance with the General Data Protection Regulation (EU 2016/679), which is the strictest regulation in the world governing the protection of patients' rights and the use of health data. In accordance with French regulations, this study was conducted without the need for consent from an ethics committee. Moreover, it was conducted according to the principle of the reference methodologies of France's National Commission on Informatics and Liberty (CNIL). A privacy impact study was also conducted.

Provenance and peer review: Not commissioned; externally peer reviewed.

Data sharing statement: The datasets generated and analysed for the current study are not publicly available due to special authorization needed from the CNIL to share data. The data are available from corresponding author on reasonable request following prior authorization by the CNIL.

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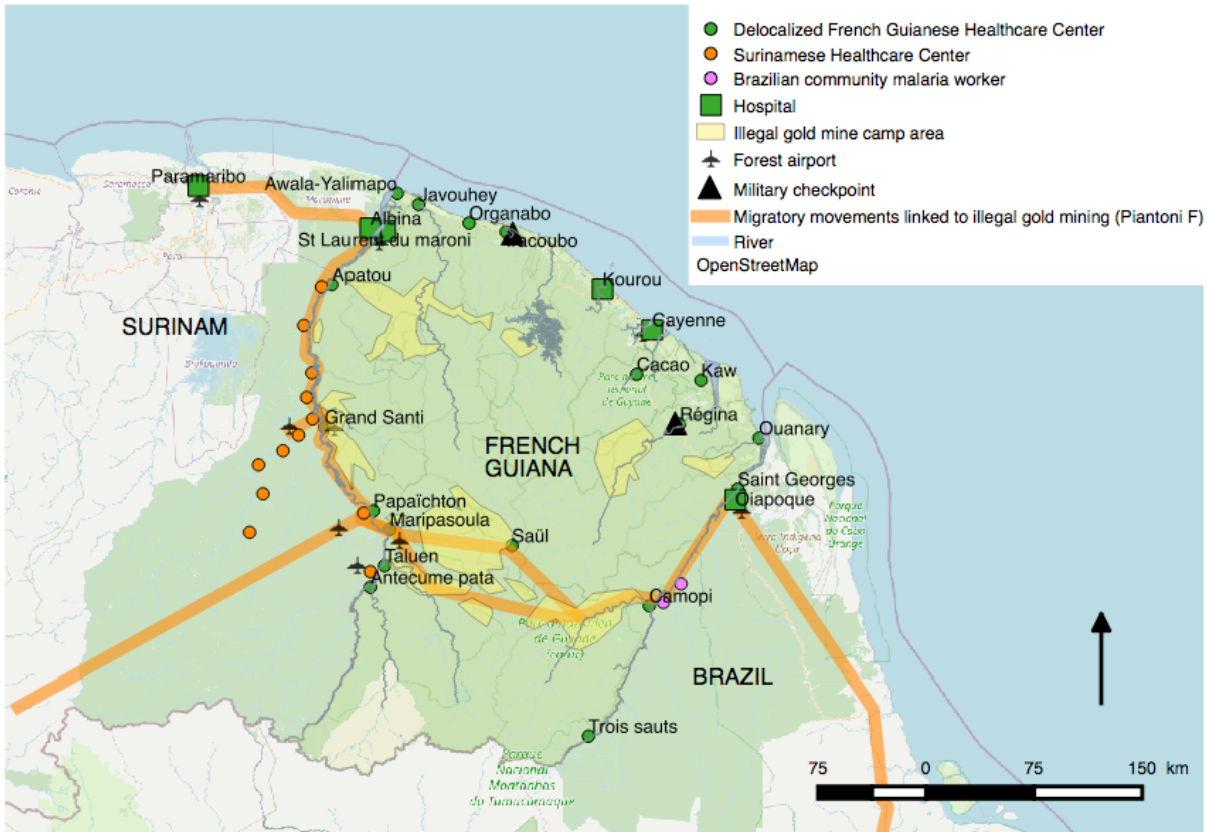
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26 **Figure 1.** Map of healthcare centers, gold mine area and migratory movements linked to illegal gold
27 mining in French Guiana which were previously reported by Piantoni F. Map was created by
28 using QGIS Geographic Information System. Open Source Geospatial Foundation Project.
29 <http://qgis.osgeo.org>
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Standards for Reporting Qualitative Research (SRQR)*

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

Page/line no(s).

Title and abstract

<p>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</p>	<p>Done, Page:1 Line:2</p>
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	<p>Done, Page:2 Line:1</p>

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	<p>Done, Page: 3 and 4</p>
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	<p>Done Page:4 Line:17</p>

Methods

<p>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**</p>	<p>Done Page: 4 Line: 31 Page 5 Line:11-14</p>
<p>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</p>	<p>Done Page: 5 Line: 24</p>
<p>Context - Setting/site and salient contextual factors; rationale**</p>	<p>Done Page 4 Line 31- 41</p>
<p>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**</p>	<p>Done, Page:4 Line:36</p>
<p>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</p>	<p>Done Page:5 Line: 1 to 5</p>
<p>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**</p>	<p>Done method section</p>

1 2 3 4 5	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	Done Page:5 Line: 20
6 7 8	Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Done Page: 5 Line: 36
9 10 11 12	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	Done Page:5 Line: 11
13 14 15 16	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**	Done Page: 5 Line: 21-24
17 18 19 20	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Done Page: 5 Line: 22

Results/findings

23 24 25 26	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	Done, ` results section P7-P11
27 28 29	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Done, results section

Discussion

32 33 34 35 36 37	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	Done, discussion section P11-12
38 39	Limitations - Trustworthiness and limitations of findings	Done, Page: 12 Line:12 to18

Other

42 43 44	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Done Page: 12 Line: 16
45 46	Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Done

*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.

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**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
DOI: 10.1097/ACM.0000000000000388

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