Alliance for Public Health

Romanian Angel Appeal

#SOS_PROJECT

Health practices, experiences and perceprions among people living with HIV/AIDS

Qualitative research report / 2021

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The research was conducted within the framework of the Romanian Angel Appeal Foundation's project "#SOS_Project: Partnership for sustainable public policies in the area of HIV/AIDS prevention", funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria. The project was coordinated by Camelia Raita.

Acknowledgements

We especially would like to thank people living with HIV and their partners for their confidence and willingness to answer our questions. They have shared with us not only positive experiences of coping with the disease, future plans and aspirations for a better life; but also fears, discrimination and isolation. We hope this report best reflects their perspectives.

Recruiting study participants would have been much more difficult without the involvement of civil society partners - UNOPA (National Union of Organizations of People Affected by HIV/AIDS), "Eu sunt! Tu?" Association and Sens Pozitiv Association. For many people living with HIV in Romania, these organizations, through the services they provide, represent an important element of balance.

During data collection, the research team received administrative support from Camelia Raita, project coordinator at the Romanian Angel Appeal Foundation. The authors of this report also benefited from Andreea Stănculescu's support[1] in the logistical organization of the discussions and the transcriptions, and from feedback and methodological guidance from Manuela Sofia Stănculescu[2], whom we thank. Discussions with research participants took place at the headquarters of the Romanian Centre for Economic Modelling Association.

The final version of the report was reviewed by Alexandru Toth and edited by Ionuț Ardeleanu (Romanian Angel Appeal Foundation).

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Introduction

HIV infection can be easily prevented and, once on treatment, properly managed. However, in practice, both at policy and individual level, there are still many battles to be fought. 2020 is a landmark year in the fight against HIV. The ambitious targets for this year, to which Romania, along with other countries that are part of the World Health Organization, has signed up, aim to have 90% of people living with HIV know their status, 90% of people who have been diagnosed receive antiretroviral treatment and 90% of people on treatment have undetectable viremia[3]. Romania partially meets these objectives.

As of 31 December 2019, 16,486 people were registered with HIV/AIDS in Romania[4]. In the last 10 years, the number of people diagnosed with HIV has increased by almost 30%, by an average of 684 people per year[5]. Of the nearly 10,000 newly diagnosed cases from 2009 to date, more than 60% are among the heterosexual population, followed by injecting drug users (IDU, 17%) and men who have sex with men (MSM, 14%)[6]. Data from the end of 2019 show that the trend over the last 10 years continues in the heterosexual population (62% of newly diagnosed cases come from the heterosexual population)[7]. In terms of IDU, the number of newly diagnosed cases has steadily decreased from 2012 to date, reaching almost 11% of all cases in 2019 (86 people). Newly diagnosed cases among MSM, on the other hand, more than doubled compared to 2009, accounting for 24% of all newly identified cases in 2019 (192 people). It is noteworthy that between 2009 and 2019 there is a high, relatively constant proportion of positive tests recorded among HIV contacts. In 2019, 89 out of 911 tests were positive.

Most newly identified cases in 2019 came from the male population (75%). The highest shares are among the 30-34 and 40-49 age groups, respectively, for both genders (over 20% of the total by gender)[8].

HIV/AIDS testing is still rather late in Romania. In 2019, 59% of newly detected cases were diagnosed late (CD4 < 350 cells/mm^3), a slight decrease compared to 2016[9] or 2018[10], but above the European average[11].

In 2018, out of an estimated 17,000 people living with HIV, 88% were diagnosed, 77% were receiving specific treatment, and 73% had achieved viral suppression[12]. In 2019, the percentage of those receiving antiretroviral (ARV) treatment exceeded 90%. Thus, out of 13,863 patients actively registered in one of the nine regional treatment centers nationwide, 91.3% were receiving treatment (ARVs). According to

[3] UNAIDS (2014).

[4] Monitoring has been carried out since 1985. The total number of people diagnosed since 1985 is 24,9936.

[5] Statistical information by year can be found in Annex 1. HIV statistics in Romania.

[6] According to data provided by the HIV/AIDS Monitoring and Evaluation Department of the National Institute of Infectious Diseases Prof. Dr. Matei Balș.

[7] The percentage is calculated from the number of newly diagnosed cases. The number of new cases for which the method of transmission is unknown is very small in Romania (12 cases in 2019), not significantly affecting this percentage.

[8] The distribution by age and gender is shown in Annex 1.

[9] In 2016, 61% of new cases were diagnosed late (Ministry of Health, 2018).

[10] European Centre for Disease Prevention and Control/WHO Regional Office for Europe (2019).

[11] European Centre for Disease Prevention and Control/WHO Regional Office for Europe (2019).

[12] ECDPC (2018).

care cascade data provided by the Department for HIV/AIDS Monitoring and Evaluation, 78.6% of people on treatment were tested for viral load in 2019 and of these, 7,274 people are undetectable (VL <50 cp/ml). The 73.2% in viral suppression is still far from the 90% target.

The policy vision is that by 2021 "Romania will become a country where all people living with HIV infection or diagnosed with AIDS, as well as people in vulnerable groups at high risk of HIV infection, have equal, unconditional and continuous access to prevention, treatment, care and social services" (Ministry of Health, 2018: 6).

This research provides information on how the reality of people living with HIV in Romania is built through everyday experiences. It also informs, from a subjective perspective, the extent to which the vision set at policy level is reflected in the everyday reality of people living with HIV.

Methodological issues

This report is based on data collected through qualitative methods – semi-structured interviews – in a research conducted by the Romanian Angel Appeal Foundation (RAA) and funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria.

Data collection took place from 29 January to 31 March 2020 and included 21 individuals.

Respondents were identified with the help of civil society partners active in the MSM and HIV/AIDS sector[13]. The main selection channel for the MSM was through UNOPA[14] which sent a message about the research to the internal group for communication with its members. For the other categories of respondents, the snowball method was applied. Although the final sample of respondents maintained a distribution in terms of sexual orientation/gender/age, it still shows a self-selection effect. People who can be described as active in their groups, who are concerned and informed about the disease, contacted the research team and were interested in taking part in the research.

The interviews were face-to-face and recorded. Only in 4 interviews conducted after the establishment of the state of emergency on COVID-19 were the interviews conducted online. The recording of the interviews was done with the written consent of the participants.[15] All recordings were transcribed verbatim and cover a total of 187 pages (see Verbatim Transcripts Report). For participating in the research, respondents received a shopping voucher worth 100 lei.

The interviews focused on two large groups of people living with HIV - men who have sex with men (MSM) and heterosexuals (HS), the two main groups with the highest rates of new infections in Romania. Particularly in the case of the second group, the large transmission of HIV/AIDS in the heterosexual

[13] This is about non-governmental organizations: The Association Eu sunt! Tu?, the Association Sens Pozitiv and the National Union of Organizations of People Living with HIV/AIDS/

[14] The National Union of Organizations of People Living with HIV/AIDS.

[15] See the Informed Consent template in Annex 2.

population draws attention to serodiscordant couples, which according to international studies[16] can be considered as the main source of new infections in the heterosexual population.

19 HIV-positive (HIV+) and 2 HIV-negative (HIV-) partners from serodiscordant couples were interviewed. The socio-demographic profile of the interviewees is presented in Table 1.

Respondent type	Men who have sex with other HIV+ men	HIV+ heterosexual people	HIV- serodiscordant couple partners
TOTAL	9	10	2
Age category			
- 18-24 years	2		
- 25-34 years	4	7	2
- 35-50 years	2	3	
=>50 years	1		
Gender			
- Male	9	5	2
- Female		5	
Couple relationships			
- HIV+ couple	2	4	
- Serodiscordant couple	0	3	2
Number of school years			
- Minimum years of school	10	12	
- Maximum years of school	21	19	
Job			
- Full-time employee with employment papers	5	3	1
- Part-time employee with employment papers	1		
- Self-employed entrepreneur	1		
- Unemployed	2	4	
- Homemaker		1	1
- Unable to work		2	

Table 1. Socio-demographic profile of respondents

The vast majority of respondents are from Bucharest (19), one from Arad and two from Ploiesti. Respondents range in age from 21 to 56, with most in the 25-34 age group. Given the target groups covered by the research, the number of men we spoke to exceeds the number of women, although in the heterosexual group, the ratio between the two genders is equal. Of the 21 respondents, six are part of couples where both partners are HIV positive and five are partners in serodiscordant couples.

[16] Kim et. al (2016), Eyawo et al. (2010), Dunkle et al. (2008).

Most of the respondents have a university degree, either short or long-term higher education. Nine people reported having completed the educational equivalent of 12 years of school - high school, or less. In terms of employment, half of the respondents are formally employed or self-employed and half are unemployed, homemakers or unable to work.

Respondent type	Men who have sex with other HIV+ men	HIV+ heterosexual people
TOTAL	9	10
Year of diagnosis		
- The oldest	2013	1990
- The most recent	2019	2019
Source of infection		
- Unprotected sexual intercourse with an infected person	6	3
- Joint use of drug injection equipment with others		1
- From the hospital (transfusion, vaccine, dental intervention)	1	6
- Unknown	2	

Table 2. Medical profile of respondents

In terms of relationship to the disease (Table 2), 6 people were infected as children, some immediately after birth and others at an early age, and 13 people were diagnosed as adults. Most of the respondents (nine) say they became infected through unprotected sex with infected people, with a higher proportion among men who have sex with men. All HIV-positive respondents were on treatment at the time of the interview and regularly monitored their viral load (viremia).

Data analysis

The interviews covered multiple dimensions of "life with HIV", from personal knowledge, attitudes and perceptions of the disease, to couple or family dynamics, access to health services, general community and societal attitudes towards HIV or the impact of national policies felt at the individual level. The broad themes covered in the interviews reflect the complexity and, at the same time, the difficulty of identifying and analyzing the health behaviors of people living with HIV.

Beyond condom use and adherence to ARV treatment, which are the indicators most often examined in studies of health behaviors, this research also collects data on structural factors that are more remote from individual action, but which may affect the health behaviors of people living with HIV.

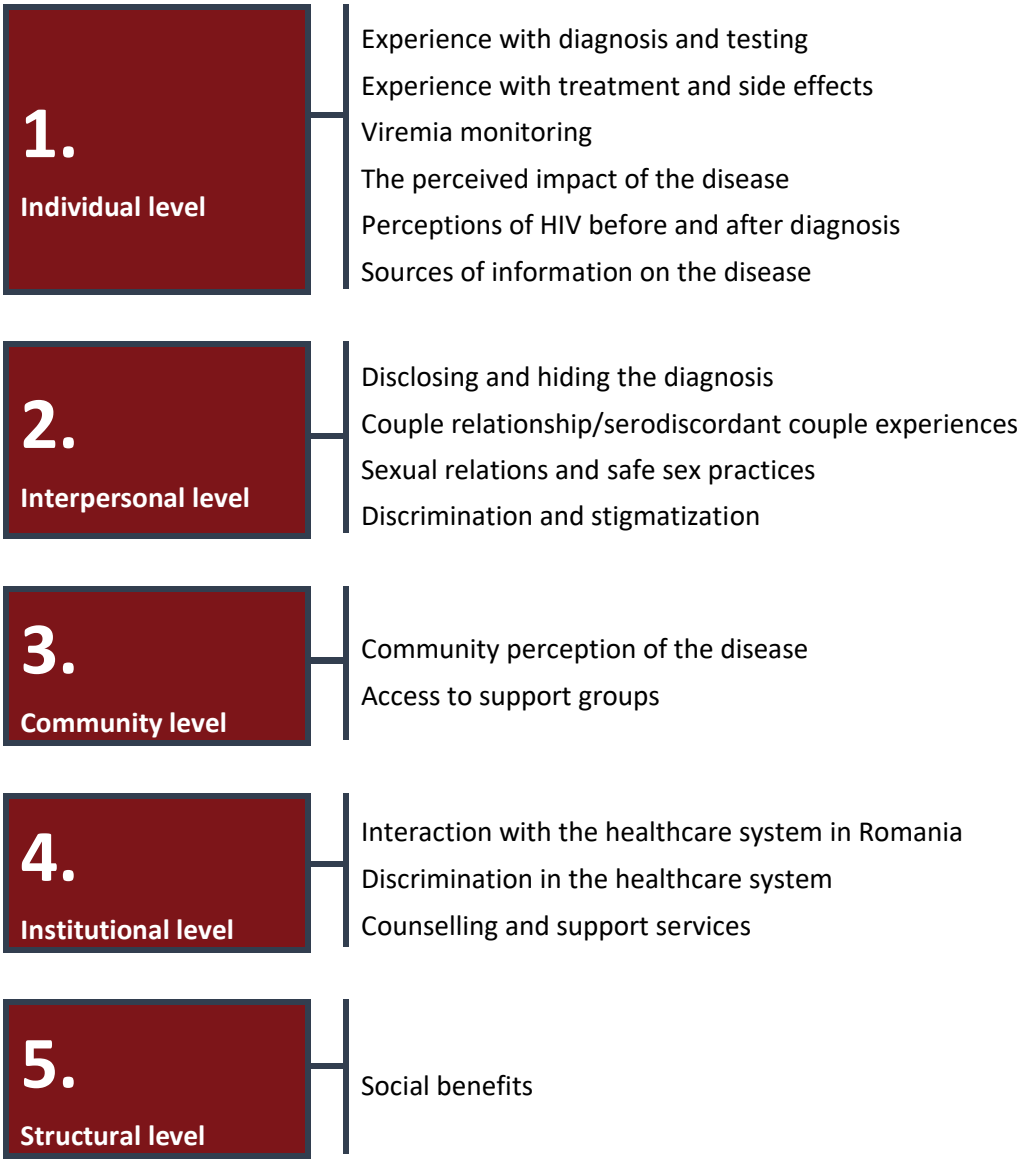
The analysis proposed in this study uses a multi-level approach that allows structuring the information collected in the qualitative research and provides important clues as to where interventions can be targeted. The topics discussed with the interviewees were grouped starting from the rather theoretical levels proposed by Michelle R. Kaufman, Flora Cornish, Rick S Zimmerman and Blair T Johnson (2014) in order to identify, from the perspective of people living with HIV, possible difficulties/ problems they face.

The social-ecological theoretical model developed by Kaufman, Cornish, Zimmerman and Johnson (2014)[17] brings together all the factors that can influence the health behaviors of people living with HIV and which can in turn inform interventions for HIV transmission prevention, treatment and/or care. The model includes a range of variables and processes from different studies and intervention models, which are grouped into 5 levels from micro to macro: individual level (information, perceptions, beliefs, emotions), interpersonal level (family and support relationships), community level (group-level perceptions and social norms), institutional level (healthcare system, such as quality of services, confidentiality or availability of resources) and structural level (factors such as economy, political climate, funding or force majeure events). The variables brought together in the model represent a range of topics that can be addressed to understand, from a comprehensive perspective, the health behaviors of people living with HIV and the factors that may affect these behaviors. The model is detailed in Annex 3.

The analysis is structured along the five dimensions shown in Figure 1. The information presented at each level represents the perceptions of people living with HIV and their partners about the issues they face/interact with at each level.

[17] As well as many others that represent different applications on Bronfrenbrenner's ecological model (e.g. Frew et al, 2016) or that bring into question structural aspects that influence health behaviors (Gupta et al. 2008 or Seeley et al. 2012).

Figure 1. Structure and topics of analysis



Where possible, the perspectives/experiences mirrored during the analysis were those of:

- people who were diagnosed as children and those who were diagnosed as adults,
- people diagnosed as adults who took the risk (unprotected sex, injecting drug use) and those who did not take the risk (infections at the dentist/ hospital/ following abuse),
- heterosexuals and homosexuals,
- single people and couples,
- women and men,

1. HIV from an individual perspective

1.1 Experience with diagnosis and testing

1.
Individual level

HIV/AIDS DIAGNOSIS
Individual experience with diagnosis and testing

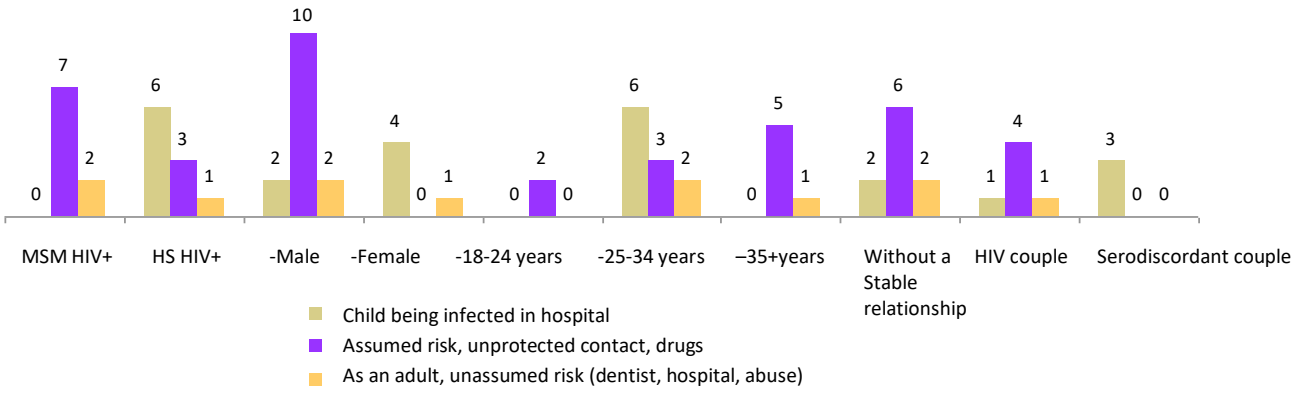
When did you get the diagnosis? How old were you? How was it when you found out?

In what context did you decide to get tested for HIV/AIDS?

1.1.1. Diagnosis

The sample includes 19 people infected with HIV. Of these, 6 people were infected in childhood, some immediately after birth and others at an early age. Most of them became aware of the disease in childhood, but there are also (2) cases who only found out after 20 years, in certain circumstances. The other 13 people (so the majority of the sample) learned their diagnosis as adults. For most of them, the infection was not a complete surprise, as "I've also stepped in the cracks" (M, 42, HS). However, in 3 cases there are also life stories where HIV infection was totally unexpected. The distribution of cases according to time of diagnosis and characteristics of interviewees is given in the figure below.

Figure 2. HIV/AIDS infection by interviewee characteristics



Note: MSM = Men who have sex with men; HS = Heterosexuals.

Most people infected in childhood learned about the disease and how they were infected at ages over 10 from their parents. But there are also cases where parents "didn't really know either" what the disease meant and preferred to hide the information from their children. I found out "when I was 11. Incidentally because, well..., I kept swallowing pills and my parents kept gave me all sorts of explanations [...] and I stole the medicine bottle to read the package insert and that's how I found out. And after I found out, I didn't tell anyone, I kept it to myself somehow so I could figure out exactly what this thing meant." (F, 30

years old, HS) There are also cases where neither the child nor the parents knew and only find out about the disease after they become adults and are looking for a job.

> ” In October 2016. I found out by accident ... Yeah, well, I took an XXX course, got a job. At that job I had to undergo some tests for occupational medicine. I signed the employment contract, gave all the diplomas and in the occupational medicine department, I took the HIV, hepatitis B and C tests. After a few hours, very few hours, the manager of the private clinic called me urgently [...] I went there and she told me: You have HIV! We tested the blood sample twice, both times it came back positive. She sent me urgently in the morning to the manager of the hospital, Mr. Străinu Cercel, after two weeks the results came back and he told me: Miss, you have had HIV since childhood, I had a huge viral load and I was an exceptional case because I survived many years with HIV [...] They don't know exactly how I was infected. I just guessed, yeah. I had an emergency operation, I had peritonitis, appendicitis in the last stage, I went to the hospital, they told me: in two hours we are going to operate on you, otherwise you will die. They did emergency surgery on me and after three weeks they had to cut me alive because I had a huge infection, it was popping inside me...fever almost 41...I sweated a little, I looked...I was only 11 years old and I survived fine and dandy until I was 28 when I found out." (F, 31, HS)

A particular case is that of a young man who grew up in a foster home and was diagnosed when he was 14, received treatment, but did not learn of his infection until he was 23 from his doctor (he is now 32). This shows that, at least in the early 2000s, infected children in the special child protection system, even if they were receiving the prescribed medication, were neither informed nor prepared about prevention, transmission and protective practices. There is no recent data to show whether the situation has improved or not.

People who have been infected as adults fall into two main subgroups. The first is the group of risk-takers who have been informed about the risks of infection associated with certain behaviors. They generally respond simply (with a high degree of certainty) or more elaborately (when the possibilities are multiple but involve known elements of risk), as in the examples below:

> "Most likely through unprotected sexual intercourse." (M, 21, MSM); "I've had unprotected sex many times and expected to mess it up any time now" (M, 42, HS); "I was in a relationship with a guy, I was doing safe sex at first, there were two situations where I got away without a condom..." (M, 34, MSM); "Yes, in 2018, I know, it was my ex-partner." (M, 23, MSM); "Let's say I was confident enough and I ran into a psycho." (M, 37, MSM); "I don't know...I think...it was a party somewhere out of the country, in Paris, a birthday party and there was more stuff going on there with strangers." (M, 44, HS); "It's a personal thing and it's not...it's not about drugs or...anything. So, it's something from an old relationship and I promised him I would never divulge that" (M, 34, MSM);
>
> "From the drugs, from the syringe." (M, 34, HS);
>
> "Around the same time, I had an element of risk, not being protected and around the same time in a club, I got stung, but I wouldn't know what caused it and how I got it. At the same time, I also went to the dentist. So, I don't know. I'm inclined to actually believe that it happened sexually, and I want to believe that because I want to not believe that it happens through dentists or through pricks, but I don't know, I can't tell." (M, 42, MSM).

The second group is much smaller and includes people who have become infected unexpectedly because of other people's inappropriate behavior, such as those infected at the dentist, or lied to and abused by partners.

> "I had a hunch with the dentist...I had tooth pulled and I had problems after that period that the spot wouldn't close...but I don't know anything for sure." (M, 28, MSM);

"In other words, the partner I was with at one point sexually assaulted me, it was a pretty nasty assault because there was some muscle damage, therefore it was opening straight to the bloodstream and that's pretty much how I got it." (M, 27, MSM); "... I have been married before and then during the marriage, from my husband." (F, 36, HS).

1.1.2. The testing

For people who were infected as children, the decision to test was made by their parents or grandparents. As the interviewees point out, the decision was not one to test for HIV/AIDS *per se*, but rather a quest to "get to the bottom" of a deteriorating health condition with increasing and worsening symptoms (fainting, bedridden, paralysis, etc.) for which there was no diagnosis and no cure. The narrative about the testing shows how complicated the process was, how many different kinds of doctors of different specialties and tests they had to endure to finally reach a diagnosis at a relatively advanced stage of the disease, precisely because of the delays in the diagnostic process.

"*But do you know how your parents decided to test you at eight?* - I know. It wasn't a testing decision, because for a long time, until they found out, I had always been weak, would catch a cold frequently, they had done all kinds of tests, I had been to all kinds of doctors. I remember that time very well, and nobody knew what was going on, what I had, what the problem was. And the moment was that I fainted on the street on my way back from school and a cousin who lived near the school carried me home in her arms and from there my parents, very scared, left with me in their arms, somewhere in Ploiești, and they entered by chance, that was the only place where they had not been, at the infectious diseases ward in Ploiești. And they went in there by chance and that's when the doctors there, the nurses, said let's do a test and see what's going on." (F, 30, HS)

Of the people (the 10) who engage in some risky behaviors (unprotected sex, injecting drug use), the majority (6 people) are informed, got tested, and get tested regularly at least once a year or when they change partners:" the relationship had ended and I wanted to see which way to go, so I tested myself" (M, 23, MSM).

" Well, in 2011, I talked to the person I was talking about earlier...he said...he says...like this, like this, like this...I've been with someone else...I say ok, it's no problem if you've...that's it...you've ruined me too, but that's life, we move on. Well, he says... aren't you worried?! No, because I know what it is, I know how it is transmitted, I know how to treat it, I went through the same stuff as a child. So I was informed from a young age. Until I was 18 I grew up in a foster home and ... there were certain acts...like...you know what I mean...where children were subjected to unimaginable rapes and I knew then that this could happen anytime and so between us. I had colleagues who got hepatitis by being subjected to those rapes... I was lucky enough to have a very protective teacher and was then shielded from this stuff. [...] And then I informed myself in advance. Both in school and on the Internet ... the information was at hand. So I immediately went to a private clinic to get tested." (M, 34, MSM)

So, they got the diagnosis after regular testing. The other 4 people, although assuming risky behaviors, only ended up getting tested following signs of disease, "because I wasn't expecting it". However, some of them (2 people), because they were informed and aware of the risks, went and requested HIV/AIDS testing from the outset, even if along with testing for other conditions. For example, the interviewed injecting drug user was tested while: "I was in prison, I was in Jilava and I had a cold that had not gone away for two weeks already. I had also heard that guys I had been using with were infected, so I told them to take me to the hospital to get tested, and that's how I found out." (M, 34, HS). Another interviewee was tested for HIV/AIDS "because it was bundled with a syphilis infection":

> "I got tested because it was bundled with a syphilis infection. Yeah, it was bundled... I mean wait a minute, if it's syphilis... because I knew the signs of syphilis... I was lucky I got the signs that other people don't. And I say, whoops, if this isn't HIV then I don't know what it is, don't tell me how... so the shock was already somewhat cushioned... because I knew... I saw it coming. I'm saying, it doesn't work anymore... and then I saw that it's HIV 1... well ok... it was a trauma obviously. I stood between life and death. I didn't want to be neither alive nor dying, you know? Floating above it like that...God, terrible." (M, 42, HS)

Only 2 of these people found out about the infection by chance: "I didn't decide to get tested for HIV. I found out by chance, following medical tests, and naturally I had to go ahead with the actual test and treatment." (M, 21, MSM)

Finally, the third category of people, who became ill unexpectedly because of inappropriate behavior by others, decided to get tested for HIV/AIDS as part of a more general medical testing process. The victim of sexual abuse found out in court that the abuser was infected and so decided to get tested. The woman infected by her husband got pregnant "and then I went to the family doctor to get the usual pregnancy tests and I found out and that's how I ended up getting an HIV test." (F, 36, HS)

> "The eyelid on my left eye was inflamed and very bruised. And we did a lot of tests and still nothing came out. And a dermatologist suggested I get an HIV test. The infectious diseases department in Arad gave me a negative result because I had CD4, nine... And I decided to have it checked again, do some more tests and I went to a private practice, it came back positive. I didn't stay in Arad, I came immediately to Bucharest, I didn't wait for them. Here it came out positive the first time...that lasted three days...then they called me back to the hospital, took the results and they collected more blood for the rest of the tests: CD4, viremia, usual tests, hepatitis tests..." (M, 28, MSM)

Access to the test and the test itself only posed problems for people from cities other than Bucharest. The majority of the interviewees (14 out of 19) were tested for the diagnosis at the National Institute of Infectious Diseases Matei Balș in Bucharest. The others, from smaller towns or rural areas, who as children or as adults went through the initial testing process somewhere outside Bucharest, indicate that testing was a lengthy process that involved repeated trips to larger cities, many hospitals, many specialists and the “money envelope”.

> “- Why so long, I mean three months is a long time not to get your treatment or ... what happened that took so long?” - I didn't think it through. I found out because I had an infection in my anus and I had to have an operation and I went through some total tests where HIV came out at the hospital and I'm from a small town...I was sent to a bigger city that was nearby for a concrete test and it took at least a month...it took until...it finally came, I had to go there in person again, open the envelope because they wouldn't tell me on the phone and I don't know...it took three months to get things sorted out." (M, 21, MSM)

1.2 Experience with treatment and side effects

1.
Individual level

THE RELATIONSHIP WITH THE DISEASE
The treatment and side effects

Treatment information - if you are taking any, how long have you been taking it, how many pills are you taking, what are the main difficulties in taking the treatment (if any)? Are you able to take the treatment as prescribed by your doctor without interruption?

What are the main side effects?

1.2.1. The treatment

Of the 19 people interviewed, 5 have been on an HIV/AIDS treatment regimen for between 11 and 20 years. These are people who were infected as children (not the one who found out about the disease at 28 when she was looking for a job). Another 9 people have been in treatment for 1 to 7 years, while 5 people have less than 12 months of treatment experience.

In relation to treatment regimens, interviewees brought up seven main topics which are presented below.

(1) Tablets versus injectable

At the time of the interview, all interviewees were on a pill-based regimen ranging in number from 7 to 1 per day. Almost all of them said they either only take them in the evening or prefer to take them in the evening because it does not affect their daily activities, although sometimes they forget to take them because they fall asleep.

(2) Change of treatment regimen

Despite differences in the length of time spent in treatment, the vast majority (15 people) have changed treatment regimens over time. Only 4 people have had experiences with a single treatment regimen, and these are generally people who started treatment less than 12 months ago. There is one case that has been treated for 7 years with the same treatment regimen: "Only one and the doctor did his best to keep the same regimen, ... in the evening, three pills, every day." (M, 44, HS)

> "This treatment thing is so frustrating to me at this point in my life. I've changed some treatment regimens if I'm not mistaken somewhere around 3 or 4 treatment regimens. With the last one being in 2008 and I changed them...well...initially because they weren't working for my body and then there were times when I didn't want to take them anymore and well, I ended up...there was one critical stage where I had to go to the hospital because I hadn't taken my treatment and somehow that was my 'wake-up call' that...after what I saw in the hospital...no more, no more! I don't want to see any more of that. I don't want to get to that stage, so I'll take them. And I stopped at a regimen in 2008..." (F, 30, HS)

In general, treatment regimens were changed either "because they didn't work for my body", or because certain medicines were not available, or because of unbearable side effects or in the context of other conditions.

"- *How many times has your treatment regimen changed*? That I don't know...I know the second-to-last time, I even turned to Fuzeon. With Fuzeon being an injectable regimen...it was at that time the most advanced. I, in general, have not had any problems with any kind of treatment regimen, i.e. no side effects, no vomiting...no problems with any regimen so far. But following that regimen with Fuzeon, I had a lot more regimens because in the meantime I became resistant for several reasons: I wasn't taking them, my body didn't have as much fighting power because I didn't have as good a quality of life as I have now, i.e. regular meals, eating as healthy as possible, hydrating on time and so on...I think these things mattered too. And for about 7-8 years, I've been taking this 4-pill regimen...anyway I'm said to be multi-experimental. It seems to have worked, at present I am undetectable." (M, 32, HS)

"We had the first regimen, the doctor changed it because I got pregnant and it wasn't suitable for pregnancy. Then I don't know, they ran out of a certain medicine and changed it again. And now they changed it so that I only take it in the evening, because I have problems with my gallbladder in the morning and I used to vomit them." (F, 32, HS)

The change of treatment regimen is decided by the doctor. But in some cases, change proves to be a difficult undertaking, mainly for bureaucratic or hospital budget reasons, even if it does not deliver the expected results or causes serious side effects.

"Yes, I spoke to the doctor who took me in at the time, who was very OK, but she was at the Military Hospital, at that time the Military Hospital had the infectious diseases department within the Institute... in the courtyard of the Matei Balș Institute. And I talked to the doctor, but they couldn't make the decision to change a treatment as easily as the ones at Matei Balș. They needed more approvals, more misery, more paperwork, and I kept telling the doctor, I kept telling her...and she was testing me, she tried at one point and did my viremia earlier, to see how the treatment was going, and the viremia was going very well. It was good for the immunity as well. But, I was in bed, I couldn't do anything. I also had to quit my job. Then I went to the hospital and told the doctor I wasn't taking them anymore. I can't anymore because they kill me before the disease does. My eyes were bruised, my lips and fingernails were turning blue. Hearing that, he said well let's take them this month and... ok I'll take them, but I'll bring them back to you. I don't swallow them anymore, I don't swallow them anymore, I'd rather die than...I couldn't take it anymore. I went to the psychiatrist, I took painkillers, I took sleeping pills, I took all kinds of crap. Nothing, nothing was working. On the contrary, those sleeping pills made me worse, they made me worse because they were giving me a drowsiness I couldn't satisfy. I mean the sensation...I mean the side effect of this Stocrin was so strong that it counter...how shall I say...counteracted the effect of the sleeping pills. And for two months I didn't take them. It was only afterwards that the doctor was able to change my regimen." (M, 37, MSM)

While the majority of participants indicate that after identifying an acceptable regimen "no one cared if we changed or didn't change the regimen", (F, 30, HS) even though newer treatments have emerged that might be more effective and easier to tolerate, a minority of interviewees claim that, theoretically, treatment "should be changed every 3-4 years, not every 10 years" (M, 27, MSM) and recount how they found a doctor who listened to them, understood them and found a solution to identify a more suitable regimen for their specific problems.

" I changed the treatment twice. I didn't change it because I developed resistance, but because after these conferences I attended they told me that it's better to change treatment every 3-4 years, not every 10 years. I had 17 years of dancing and I was all "fiber". Since the treatment I've reached a weight of 85 kg in 4 years. I should mention that my height is 1.65. It kept settling, I had the impression that even if I breathed I would get fat. [... *And he found a doctor who* ...] she was a little skeptical as well, she's tied by the hands by the system, she can't always give you everything... When I told her that I wanted to change my treatment because I was starting to gain weight, because I had all kinds of sudden changes of mood, because I seemed to get depressed and it didn't work, even though the tests were ok, I told her that the treatment would change after 3-4 years... And she gave me another treatment, the one I'm on now." (M, 27, MSM)

(3) Discontinuation or delay of treatment by the infected person

In behavioral terms, all participants in the study reported that (at the time of the interview) they were following the treatment "diligently", at worst with minor lapses.

> "*Are you able to take the treatment as prescribed by your doctor without interruption*? - Yes, I have no problems in that respect. It happens to me extremely, extremely rarely...I don't know once, twice a month, to miss a pill. But it happens to me very rarely...due to a lot of work, tiredness that I fall asleep and when I wake up I realize it's much too late to take the pill." (F, 30, HS)

> "Without discontinuing it, I made it, same time approximately, depends. But I don't deviate very much. With few exceptions, once every few months if I'm at a party and I forget to take my dose from home not knowing the event itself is taking longer." (F, 31, HS)

> "Yes, there are pills. I only take them once a day, I prefer to take them in the evening at bedtime. I have a more chaotic schedule and find it very easy to take them to bed at night." (M, 37, MSM)

> "No discontinuity. I'm never supposed to discontinue it. Because if you discontinue it for more than a few days, resistance builds up and you die straight away. No doubt about it." (F, 31, HS)

> "I don't have a problem with the treatment, I take it, I'm conscientious about it, I realize it's my life at stake and I don't play with it. Maybe with others: that I don't eat healthy, or I smoke more, but with pills, no." (F, 36, HS)

> "I'm on Isentres and Kivexa. Isentres is taken twice daily. I always take Kivexa in the evening. Since I've had treatment, paradoxically...in my life I've never held a head to tail treatment, this one I've never forgotten. [...] So it's not to be trifled with...absolutely not at all and I keep it as strictly as I can." (M, 34, MSM)

In rare cases, interruptions of a few days (less than a week) are reported due to causes such as panic attacks or stockpiling of "black days" medication (see topic 6 below).[18] However, 6 of the 19 people reported discontinuing or delaying treatment for months or even years during their lifetime. Such situations seem more common among study participants who were infected as children and for those infected because of the inappropriate behavior of others. These people were neither prepared nor informed, suffering a severe shock when they were diagnosed and needed time to assimilate the information and develop a new way of life. The narrative of these people stands out:

- The need for a period of psychological adjustment, all the more so as the HIV/AIDS diagnosis was accompanied by other unfortunate events, plus separation from the partner.

> "It was a shock to me because I, I had advised all my friends to go get tested, to get protected, to...whatever...and I had been tested a month before I hooked up with XXX and the tests had come back negative three months before. I just couldn't go into treatment...I couldn't continue with it because I realized at the time that once you go into treatment, you only come out of it when you die. And psychologically speaking for me it was a threshold that I said I wasn't able to cross until...my doctor didn't agree with this attitude of mine, but she had to accept it because my tests...because I found out from the beginning, my viremia was very low, below a thousand... My partner's viremia was very high, but he had a very good immunity, I did not. I was a "workaholic", like now, I worked a lot and somehow my immunity was always around 300, 400. Even if the viremia was low. And I kept it up as long as I could without going into treatment until my partner's situation worsened because he was buried in work, his immune system was down and the doctor thought that as a couple it was better to go into treatment together. I agreed to go on treatment and two days later he dumped me. I started treatment on March 6, 2017. Quite some time after (2 years after diagnosis), but during this time

[18] (M, 34, MSM) and (M, 27, MSM).

I had not had sex with anyone other than my partner. I don't know...I didn't feel cheated, I don't think he did but... well...." (M, 34, MSM)

"Why did you discontinue your treatment the last time? What was the reason? "Not from the treatment, it was depression... simply because I saw that I had no luck, no success, I said what's the point of living...probably also because I see that my brother is more successful, he's lucky...well he's younger, he's 21...and I said there's no point in living...I won't take them anymore. By the time I got to the hospital, I weighed 35 kg and the CD4 was 8." (M, 32, HS)

- The crucial role parents play in the treatment of children infected with HIV/AIDS

"Since February, 2007. My parents refused treatment and they got this into my head as a child, what your parents tell you...you are influenced...if you take the treatment, you will die. And I was only on antipyretics medicines, I had fever all the time, I had seizures, I had epilepsy from the high fever...at 21 I weighed 32 kilos. After I started taking the treatment (since 2007), I got my period. I hadn't had my period until then. My CD4 was 48." (F, 32, HS)

- The influential role that partners play in HIV/AIDS treatment

[*She learned about being infected with HIV in childhood when she was 28*] I went home...I was married at the time, I'm no longer with him. My ex-husband didn't want to go to the hospital to see what stage he was in, he had his HIV test at the Sante clinic which was somewhat close, it came back positive, but he didn't want to go to see what stage he was in. [...] And he said, we have HIV, and he started reading on the Internet and came up with the conspiracy theory that HIV doesn't exist [...] And he said, let's not tell anybody, parents nobody...he just told his best friend who he worked for in online marketing and let him work from home. Otherwise, nobody else knew. I... the love of my life...will do as you say ...it's fine, we won't tell anyone, we won't take any treatment, life goes on. I found a job in Brasov, we moved there, he still worked from home. After one year in 2017, in late winter, I couldn't stay awake at all. [...] And yes, I was starting to fall off my feet [...] At some point, I decided to tell my mother. When my sister found out, she was devastated and my mother lost 15-20 kilos, it was serious. And they were trying to talk me into taking the treatment because I wouldn't take the treatment. He had brainwashed me so much that I was really starting to believe strongly that HIV didn't exist. Until I started going crazy. Because HIV primarily attacks the brain. [...] Once I went crazy, I was paralyzed. Incontinence...the incontinence came before the paralysis, the sphincter stopped, the muscles here and after that I was also paralyzed. [...] In March last year, March of 2019. You can imagine the length of time I went without treatment (about 3 years after diagnosis)." (F, 31, HS)

- The role of the doctor and the relationship between the doctor and the person infected with HIV/AIDS

"*Did you end the pregnancy then*?" "Yes, I did, yes". I ended the pregnancy and after that he went on medication, he took the medication, he recovered, within a year his immunity increased to 500 and ... well, then the doctor ... in the meantime the laws have changed, but back then, whoever had high immunity didn't go on treatment. And she told me not to go on it and I didn't and I stayed that way...but I had my immunity up. I didn't have a problem with not getting in on the treatment, first of all. Secondly, it's true that I wasn't so willing either. Also because of my mentality, of course. And I stayed that way until 6 months ago (over 6 years after diagnosis). Yes, I went for check-ups every six months. I always knew how my immunity was. In the meantime, I switched the doctor to the doctor my current husband is at and she convinced me...well, I had a much better relationship with the doctor I have now, I like her a lot more and, on this occasion, she also convinced me to go on treatment." (F, 36, HS)

"[*She found out about being infected with HIV as a child when she was 28*] You can imagine the length of time I was without treatment (about 3 years after diagnosis). If I had taken the treatment then, I wouldn't be paralyzed, I wouldn't be wearing diapers ... I still wear diapers. I don't know where to go to cure my incontinence. I'm semi-healed at the moment. It was through hypnotherapy that I cured my incontinence ... I

thought ... maybe I just realized some things. But no, the healing has not come. Now I finally met a therapist who is also a healer and works with me and helps me enormously. But this has only been for a month. Whatever, but within a month it's already had an effect and I'm super grateful. It's been an ordeal. And that's why I couldn't work because I was paralyzed. And I'm going tomorrow to sort out my employment rights so I can work. I am very capable of working, I love to work, I really enjoy it and I put a lot of heart into what I do." (F, 31, HS)

(4) Enrolment of the diagnosed person in an HIV/AIDS treatment program

The majority of interviewees (14) report that they started treatment no more than three months after the diagnosis was made, usually following further tests necessary to establish the treatment regimen. Delay in starting treatment is reported in 5 cases, being a combination of refusal[19] of the infected person to enter treatment and difficulties in enrolling in a funded treatment program, i.e. meeting the conditions of the available programs.

"And I ran the tests again, then I ran another round of slightly more conclusive tests for a sort of Swiss-Romanian program where I was only supposed to take one pill a day. When my results came back they told me it turned out not to be valid...if I had a slightly higher CD4, but I didn't and they couldn't keep me in the program. After that, they repeated my tests again so that the doctor in charge could see what kind of treatment they should put me on. And so, I took it. I was given a fairly strong medicine called Triumeg which unfortunately after three weeks I had to discontinue because I had a stroke. So, he changed my medication." (M, 56, MSM)

However, there are people who point to a lack of transparency or even "corruption", with admission to the national program perceived by most as primarily dependent on the available budget and not on patient needs or the 90-90-90[20] strategic objective.

"It depends on two things in Romania whether you enter treatment or not. There are 3 variants. When the viremia is very high, you're going somewhere over 5,000 replicates per milliliter of blood, but I know cases that didn't get in. A friend of mine had 27,000 and waited for several months before going into treatment. Or the second variant, which is the most common, when this CD4 status drops ... mind you, when I went on treatment it was below 300, and at below 300 you no longer have an immune system. More recently, the 300 threshold is no longer in place. It's 250. It's a mockery. So, to make you understand a bit: if your CD4 is 1300 and you have a cold, not the flu, a bitter cold, with some stuffy sinuses and so on, your immune system is at 800. Well, this one at 250 is a living dead. No, in Romania you have to be under 250 to get treatment. And the third variant, when the tests come back as lousy. And there are more people here that I know who have not gone on treatment." (M, 34, MSM)

One respondent talks about the strategy he/she adopted to be admitted to the national program.

"I was asymptomatic, I'm still asymptomatic, I'm in the first immunological class, in other words asymptomatic incipient HIV infection. The CD4 status was still high, the body could fight very well and the viral load was low enough. By the time the doctors saw this, I was one of the few people they had met, 3 people in 20 years who were in my situation, because many people see the doctors in the last stages and with this disease, they have told me that they administer treatment immediately, but for people who have a very low CD4 index, basically for those who are on the verge of AIDS. I was far from being there, I could have gone unnoticed. They left me for two years without treatment. [...] They told me if I don't risk it, the treatment would be too toxic and it

[19] See also the above quotes from (M, 34, MSM) and (F, 36, HS).

[20] Romania is one of the countries that signed the United Nations political declaration on the eradication of AIDS in 2016. Specifically, by 2020, countries committed that globally 90% of HIV-positive people would be diagnosed, 90% of those diagnosed would receive treatment and 90% of those treated would have undetectable viral load. Although remarkable progress has been made compared to 2016, the overall target was not reached in 2020.

would be better not to intervene. If the body resists with the infection it would be OK, that's all and it is strongly recommended to use condoms and limit myself to some very regular sexual intercourse with certain people. Nonsense if you ask me... I understand that I was fine with it, but what do I do with others, what do I do if my condom breaks, what do I do if I get drunk and don't put on a condom, what do I do if my virus level increases at some point? They didn't give any thought to these things. After two years, I had to make it up, I went to them, I said I had a fever, I had very frequent stools and I said if you don't give me the treatment because things are already getting worse I will sue you. And so, I've been on treatment for five years and for five years I've been undetectable." (M, 27, MSM)

Enrolment in the national program is described as even more complicated for people outside Bucharest. Several interviewees mention that friends or acquaintances of theirs outside Bucharest have had to wait for several months after diagnosis because there are few specialist doctors and insufficient funds available for HIV/AIDS treatment. In fact, for this reason, three of the respondents moved to Bucharest where they can live and undergo treatment.

"The point is that Bucharest is for the lucky ones. Because the situation in the country is extremely harsh. This boy I was talking about came and told me he was positive and I didn't have the guts to tell him... So he found out in September, the end of September 2018, and he had to do the other test that explains everything and because the hospital...he lives somewhere in Breaza as his home address...and they sent him to Ploiești, and in Ploiești they called him for three months, month after month, to come and do the test and every time he arrived, they said they didn't have it. So, at the end of September he found out and sometime in February he met with the doctor with results and all to determine what treatment regimen to initiate. So, in five months, this boy, in all this craziness of stress, fatigue, panic, I'm going to die, etc. he realized that the virus has gotten worse ...and when the results came back he had a viremia of 27 thousand. This is unacceptable. You tell someone he has the worst virus ever, and what do you do? You leave them...stay on the side, I'll take a look at you, stay on the side...what are you going to do? You lie there quietly? Biting your nails? For how long, five months? Of course, I don't want to think...suicidal thoughts...a lot of work. And this is close to Bucharest. I don't want to think about remote countryside areas, I don't want to think about what's there." (M, 34, MSM)

(5) "Old" versus new-generation treatment regimens

There is a consensus among interviewees that the treatment regimens available in Romania are rather "old, but they work". But, because sometimes only for these can continuity be ensured, some people explicitly express a preference for them, because for the new generation the chances are highest that they will be found only sporadically, which entails the need for further unwanted changes or adjustments to the regimen.

”... The treatment I'm on now is quite old (since 2008). It's among the first regimens to have been introduced in Romania that has some side effects that are not OK. But it works, because the tests show it works." (F, 30, HS)

"Because the treatment you get in Romania is not as smart and cool as the one in Western Europe and America. It's a fairly rudimentary treatment. Good, effective, but rudimentary. That gives you the amount of substance to kill or keep the virus away for a given amount of time." (M, 34, MSM)

"I preferred to take a simpler regimen considering the fact that in Romania it is at a pretty bad economic level, I thought logically if I am going to take the latest generation medicines that are very hard to find they might give me another excipient. Each pill contains an excipient, such as lactose. Lactose that somehow gives that slightly sweet or neutral taste, not bitter. It's just that lactose is that bad protein. It's in a very small component, but our treatment is long-term, for life or at least until other things are found. I have thought about it, if I want state-of-the-art treatment and at some point, they don't have it, they'll give me some replacements. Those replacements will come with 2, 3, 5% lactose... yet I'll get 20% lactose instead of 5% from one medicine. I'd

rather take a better but older antiretroviral medicine that's still on the market to ensure continuity of treatment." (M, 27, MSM)

(6) The effectiveness of the treatment

All the interviewees say that the treatment regimens they are receiving are working, even if they are "rudimentary", and generally mention a reduction in viremia, increased immunity or the fact that they no longer feel sick.

> "And I feel really well from them. I don't experience any side effects. Well, I changed a lot of regimens until I came across this two-pill regimen. After four months I became undetectable. And we go and get them thoroughly." (M, 34, HS, IDU)

> "My viremia has remained undetectable; my immunity has remained good and with the bonus that I no longer have the nasty conditions." (M, 21, MSM)

Although, the treatment "works", individual perceptions depend on a number of factors that introduce degrees of satisfaction with how well it works. One subject show that the results are still not fully satisfactory, but the explanation does not lie in the effectiveness of the treatment *per se*, but in the fact that he discontinued it for a while: "I feel so and so, I still have dizziness and vomiting because I discontinued it for a long time" (M, 32, HS). Another topic shows that there was a period when treatment had modest results due to misguided advice on how to administer the medication.

> "Really, with treatment it's a different story, because I started with a regimen that includes three medicines. A mid-range regimen. [...] But after about a year, by chance, I actually discovered that I had to take my medication in another way. One medicine is only taken in the evening and the other two, he prescribed two of each in the morning. I didn't get to undetectable and a year later when I went to get tested, my doctor was on leave and I went to her substitute. And the substitute asked me what meds I was taking and I told her. And she asked me how I was taking them and I told her. And she said that I was taking them wrong. I have no way of taking them wrong, I take them as they were given to me. She said, no. [...] Basically there was a problem only in terms of the administration of the treatment and not the medicines *per se*. Then I reached the undetectable level in a couple of months ... I tested myself at a private clinic and at the next set of tests at Balș, I came out undetectable there, too." (M, 42, MSM)

The most commonly used performance indicator is that viremia has reached or remains at the "undetectable" level. The most positive opinions on the effectiveness of the treatment come from people who have a trusting relationship with their doctor.

> "The current regimen seems much better to me. On the previous one I had minor side effects, but that wasn't the reason why I had to have it changed. My doctor changed, she went on maternity leave...and I was given a wonderful doctor. I feel super lucky to have this doctor. He gave me one pill...it's a cocktail...it's three substances...with very good results." (F, 31, HS)

> "When I found myself, I found myself at Matei Balș Hospital. The doctor there had a lot of patients and said it was unethical to take care of you superficially as other colleagues do, to have 600 patients when each doctor should have a maximum of 150 patients so as to have enough time to take care of them as he should... I refer you to Babeș to a doctor who was my student and I know she is good. He was very OK except he was very cold, he didn't know how to behave with a person who was in a very good health. Many doctors focus their attention only on those who are on the verge of AIDS. If I see that you are well... to the absolute minimum... come after three months or six months because even so we have no funds... what's the point of spending. And I changed my doctor again, also from the same hospital, the doctor I have now is amazing, I was able to communicate with her, she helped me a lot. It's true that she was a bit skeptical too, she's tied by the hands by the system, she can't always give you everything ... When I told her that I wanted to change my treatment because I was

starting to gain weight, because I had all kinds of sudden changes of mood, because I seemed to get depressed and it didn't work, even though the tests were ok, I told her that the treatment would change after 3-4 years... And she gave me another treatment, the one I'm taking now, I take two pills, it's first generation this treatment, but it's not really one of the most expensive. Very effective." (M, 27, MSM)

"Yes, the viremia at the beginning was 62,500, after four months it reached 550, CD4 37, it jumped to 192. And this one freaked out, how well you're doing, how cool! Yes, I also changed my diet, I no longer eat fried food, although I can eat anything on HIV treatment, you have no restrictions...except certain spices, but otherwise I can eat anything. He also tested me for hepatitis, I didn't have any hepatitis, I didn't have EpsteinBarr, I didn't have any these HIV-related infections, I didn't. Apart from syphilis which is curable." (M, 42, HS)

(7) Difficulties with access to prescription drugs

The issue most developed by almost all respondents relates to difficulties in accessing medication. The procedure for granting treatment is "very simple. Basically, you go, say who you are, they pull your file, you wait for 10-15 minutes, depending on how many people there are ...you sign in, show them your health card, sign in and take your pills. I mean, it's a very simple procedure." (M, 37, MSM)

The main problem, mentioned by the majority of interviewees, relates to the lack of certain drugs in the treatment regimens, which leads to "treatment interruptions due to the system", changing or adjusting the treatment, as well as cases of the emergence of treatment resistance which significantly reduces the effectiveness of the treatment.

"Only one regimen and the doctor did his best to keep it the same. And when there were no medicines, he offered me a pill, two pills...that there are still in the state system some syncopations like this...when budgetary changes arise or something... I take the pills every month and I sometimes have to wait to go after two pills, after three pills. But it's not the hospital's fault, it's the Ministry's fault. There is no certain possibility..." (M, 44, HS)

"There were problems with the treatment. Last year in January and this year, too ... there were problems when they didn't have a drug and gave me a replacement of that drug.... But for example, I had over the years the same drug, but with a different composition...it was Prezist, but not because it is a substitute...the first time I took 400 (mg) two pills and plus two more. After that they gave me 600 mg because they didn't have the 400 mg...I was supposed to take it in the morning with another pill and in the evening all three pills and now I take the 800mg one, three pills once a day. When they don't have it, they give another option..." (M, 23, MSM)

"There are treatment interruptions because of the system... It is not beneficial to change the treatment very often because these drugs do not come in many active substances, and the combination between them is done according to certain criteria and principles and if I keep trying, I change your regimen, I change your regimen again, at some point the virus may become resistant and I have no other regimen available and then the treatment has no effect on the virus. Indeed, I am one of the lucky ones because my drugs have been around all along, but others have not been so lucky." (M, 42, MSM)

A second problem is that the drugs are given on a monthly basis and infected people cannot "move freely" or travel for longer periods. By way of comparison, interviewees refer to the way in which medicines are dispensed in other countries; for example, they say, in the UK, medicines are sent by post every six months.

*"What about access to treatment at the hospital. Do you go monthly or how do you do it?" "*Yes, monthly. I don't even know if it lasts for a few months. Because they happen to be out of medication and then...I know a couple of years ago they were still giving them for two months, but not now. That's it." (F, 36, HS)

"I'm not leaving the country because if I were to leave the country I'm actually very afraid because I have to change treatment. I will arrive in Western Europe where I will receive a much better treatment than in Romania, I will not get used to the world there, and I will return. And guess what...the moment you change the treatment, the regimen, you can't go back to it. There are currently four or five treatment regimens in Romania, too, which keep going around and round. I'm on the lightest regimen. If I leave now and don't get used to living in England or any other country...I have to go back to...I have friends in the UK who get their pills every six months in the mail. I went to the hospital a couple of months ago and they gave me pills for two weeks because there was a shortage. And they gave them to me because I'm regular and take them constantly without interruption. In Romania of 2020?" (M, 34, MSM)

As a coping strategy, more people infected:

- claim the need for "intercessions" to obtain treatment over several months or

"I think with the right intercessions... I think it can be done, because I don't think all my friends who go away for a month and a half...I have a couple from Sibiu and they go away (abroad) all the time...they go off in five different directions...don't tell me they come back strictly for treatment. I'm sure they find a way to get it." (M, 34, MSM)

- they show how they stockpile their medicines.

" I know, for example, cases of people who were started on treatment and the first two or three didn't take it to build up their stock." (M, 42, MSM)

"I took (the treatment) until the end of the year ... then on January 7 when I went there, I was unlucky that my doctor hadn't returned from his vacation yet either...they were out of medication. And they changed it. [...] That's how we've learned to stockpile, we do it ourselves and we consider that we've been advised, when you see that you have a few pills left before it's over, then you should come...don't come when you have one or two pills left." (M, 56, MSM)

"For the last two years I've had times where I said I didn't want to do this treatment anymore because it was making me fat, I'd rather not do the treatment and have my viremia go up a little bit and get a newer drug. Or go to the UK because they give it to me for 6 months and every 6 months I go there to get it. Instead, I interrupted it to stock up. What does this mean? Either you go before the date you last took it and in other words you are already stocking up or you don't take it for a week, as it is also recommended to take a break from it, a medication break, so you can detoxify your body a bit. Because one week won't affect you, provided you've been undetectable for at least two years and don't have a high CD4." (M, 27, MSM)

Specific strategies are also developed for people living outside Bucharest. As a rule, it is the parents who collect the medicines from their home town (or the nearest town) and send them to Bucharest.

"My dad had to ride the bus 60 kilometers, go get the pills, come back to our town and then send them on the bus to me. And I had to go to the bus station and pick them up. And that's every month." (M, 21, MSM)

"You take your treatment in Ploiești, how do you do it? Your mother sends it to you?" "My mother goes once a month with my health card and picks it up. So, I don't have the health card with me. If I need the health card, I have to go home first. From a legal viewpoint, legally, you have the right to receive treatment for three months, not on a monthly basis as it is done now in Romania. I admit I was lucky. Whenever I needed treatment for longer periods, especially when I was going abroad, I would get it. This is also the reason why I don't need to go home every month to take the medication from my mother's because I already have several months' supply here in Bucharest. The moment it's over, I go home and get it." (F, 30, HS)

In addition to the lack of medicines and the need to go every month to pick them up, interviewees note the discomfort created by the lack of organization in the hospital ward where the medicines are picked up.

”... You go get your file, they call your name...there's still that thing...all the people in that hallway will learn ...then you go put it somewhere else...that's where everyone sees you...what meds you took...not all of them are ok." (M, 44, HS)

"The procedure for granting treatment is very simple. [...] The way the ward is organized is disastrous. Everything is piled up: checkups, tests, treatment, ENT, dermatology, ophthalmology, and I don't know what else - it's all there, man." (M, 37, MSM)

"And there was a hullabaloo there anyway...it was also written, it was also said...so all means of communication were used, everything in hand and patients were waiting and when they got there they were told they didn't have Triumeg, Tivikei, they didn't have Disovi and so on. I know we're more dreamy, but think about it anyway. Not to wait for who knows how many hours for your medication... “*But do you have to stand in line to get your medication?” ”* There are days and days. That depends. This procedure...it should be changed...the first queue...queue...for the files when you take out your file...then you stand in another queue, that is to say at a certain moment you are glad that there is nobody, man am I lucky, and when you come back with your file you are surprised to see about 20 people. And I don't understand, trust me, I can't understand. That depends on the people there, they are probably very ... how shall I say...so resigned...they are awfully slow. They go very, very slowly. You have to give some medication, take a good look at the medication given by the attending physician and see what you need. I don't know, I think that this should be changed...they should have a procedure, do something that people don't have...that I proposed at one point, I talked to the medical director, I said to the lady, you know what, so that you don't have problems with these queues, you know what you have to do? Open a fucking coffee shop, we would sit and have a cup of coffee and we're done with the story. And they call out to us... Only in our country they don't call out your name at all. They ask who the last person in line is and then they know who they follow...and in the meantime you can still go out for a cigarette even though it's not allowed, but there's no calling out." (M, 56, MSM)

The most disadvantaged in terms of access to medicines, however, are people with HIV/AIDS living in rural areas and small towns, as one interviewee points out.

"Look what else you could approach: the fact that it benefits people who live in towns where there are infectious disease hospitals - centers, because there are HIV-positive people who live in rural areas or in smaller or bigger towns that don't have them and they have to go regularly to these centers to get tested - the 6-month tests, for viremia, immunity and so on, and some even have to travel to get their drugs. That's what we could touch upon because there are a lot of problems here.” (M, 42, MSM)

In addition, the treatment is not combined with any kind of counselling or psychological therapy, although this would be so necessary at least at the beginning of treatment and during periods of “mental breakdown”. Counselling and psychosocial support services foreseen in the National Strategic HIV/AIDS Plan 2019-2021[21] do not seem to be operational yet. Therefore, each person finds their own way out of the crisis situation, with the help of friends, social networks or by paying for services.

"Have you had counselling before or after? - No, absolutely not. When I was telling you that he (my partner) got sick ...all I did was browse, let's say it frankly, the Internet pages, social networks and tried to see what to do and how to do it. So, quotes intended, I'm also the woman of the house and of course I didn't ask the doctor, Ma'am how I should do... (M, 56, MSM)

"I had reached a saturation like that...I didn't want to take the pills anymore...I hated them somehow...then I turned to and discovered therapy and did many years of psychological therapy. [...] Yes, that made me more aware of things...I don't know...after that I started to grow, to ask myself questions like: what is my life, what can I do, what am I good at in this world...and slowly-slowly when I started to realize that I have qualities and

[21] Ministry of Health (2018) http://www.ms.ro/wp-content/uploads/2018/11/Anexa-la-HG-Plan-National-HIV-2019-2021.pdf

that I can be useful somehow to society or to people close to me, I started to take even more care of myself." (M, 32, HS)

"I was feeling very sick from the treatment. [...] I mean, yeah, no one explains or at least they didn't take an interest...well boy, let me see, I don't know either...she probably wasn't an HIV specialist, let me call, let me see...I mean none of that stuff." (M, 34, HS, IDU)

NGOs are the ones mentioned as providing the only support for HIV information and treatment, access to drugs, equipment, psychological counselling or legal assistance. This may also be an effect of the way study participants were recruited.

"I told you, I'm multi-experimental...and if my treatment is discontinued, I become resistant. [...] And what happened last year is that they discontinued...well, out of 4 pills, one was always missing, and I heard that it was the most expensive pill in my whole regimen. And this happened every two to three months. Not having it. And then I was forced to skip the whole regimen because I didn't have this pill. Which you know very well...if a pill is missing from a regimen, it doesn't work properly and you put your health at risk. And we took the necessary steps, we sought support. And I found help with ACCEPT. I am now on my way...the moment they won't give me the pills any more ...well, before that I met with lawyers, with legal counselors, we did all the right things, we completed the formalities, evidence was gathered...now it's left at the point where...I will go to the hospital, they won't have the pill I need and then I will take the last step to sue them. In that I have to file a paper with the registry office, they have to give me some explanation why they don't have that pill and based on that paper, we can go to court..." (M, 32, HS)

"And last February, a friend of mine from ARAS helped me find a doctor in Bucharest because until then my father had been forced to go somewhere and take the pills and send them by means of a bus. And I found my doctor in Bucharest, at Balș, and he changed my treatment plan after I asked him and explained it to him." (M, 21 years old, MSM)

"After going crazy, I was paralyzed. Incontinence...the incontinence came before the paralysis, the sphincter stopped, the muscles here and after that I was also paralyzed. [...] And I know I immediately posted on Facebook, does anyone have a wheelchair I can borrow? And a boy who worked for an NGO for disabled people came right away and brought it to me in a few hours...and my mother, when she saw the wheelchair said that I don't need it...and I said, "Yes, mother, I can't walk anymore, I want to go out, take me out." (F, 31, HS)

"Honestly, yes, I still turn to ARAS, Sens Pozitiv and to information, even when pills were missing from the hospital she (person from an NGO) helped me with pills and so on." (M, 32, HS)

1.2.2. The side effects

Of the 19 study participants infected with HIV/AIDS, only 5 people mention side effects related to the current treatment regimen. The side effects mentioned are associated with "old" treatment regimens (more than 10 years old), which the interviewees have been taking for a long time, on the one hand, and with discontinuation of treatment for a longer period, on the other. These side effects most commonly relate to weight gain and fatigue, in 4 cases. More and worse side-effects are reported only after discontinuation over a period of several months.

"I don't have any kind of physical issues. I mean I can be as energetic as any person who is energetic in his own way. Sometimes I can be tired, because I have such days. However, I have all kinds of fat deposits. That's one thing I don't like. [...] I really can't stand the drugs, it's true. And maybe it is this getting pregnant thing. For which I' m not...I'm not ready and I don't know if I'll ever be ready." (F, 30, HS)

"*Adverse reactions to treatment, have there been any*? - There have been. And there are still. One of them is getting fat, there's nothing you can do about it. The second is osteoporosis...the doctor told me...that's why he

occasionally put me in one of these studies that are carried out at Balș [...] The third effect, which was a bit more unpleasant, is a kind of skin tumor that heals with the same treatment. Slowly, they appear quickly, but they heal rather slowly. Brown skin in certain areas...it's not contagious, it's nothing. It just shows up. It goes away by taking your HIV meds. [...] It's ugly... the family doesn't know." (M, 44, HS)

" I had 17 years of dancing and I was all fiber. Since the treatment I've reached a weight of 85 kg in 4 years. I should mention that my height is 1.65. It kept settling, I had the impression that even if I breathed I would get fat." (M, 27, MSM)

However, the other interviewees were keen to recall that they had experienced periods of traumatic side effects over time. These people referred either to experiences at the start of treatment or to experiences with a particular drug (most specified Stocrin).

"No, no, now I don't have any more (side effects). But in the beginning I had huge problems with the treatment. I would take four pills twice a day. Four in the morning, four in the evening. I felt really bad from it. Worse and worse every time I would take them. Nausea, dizziness, headaches, vomiting, a bad mental state, demoralized...in every way it affected me, and I would go out to the doctor's office to say and they would tell me to insist...madam I feel sick, I can't take it anymore, I keep vomiting...it's from the treatment, there's nothing I can do, you have to take it." (M, 34 years old, HS, IDU)

"I started with Kivexa and Stocrin which had quick results against the virus, but that Stocrin had some side effects because of which I basically had to quit, I couldn't take it anymore. Depression, irritability but worst of all, insomnia and nightmares. Ever since I started taking the treatment regimen, I've had really strong dizziness, like I don't know...I think I've gotten drunk twice in my life, but I've never had that dizziness, like falling down. Effectively falling off my feet, as if I had lost track of space-time. I didn't know where I was. That's how it started...I thought over time it would subside, but it didn't, actually when I was taking the pills, I had to be in bed." (M, 37, MSM)

The most traumatic experiences were reported by people for whom the start of treatment overlapped with other unfortunate life events, a combination that led to depression, further compounding the trauma.

"When I started treatment on March 6, 2017, it just happened to be the time when, XXX (my partner) left my house, I was also out of work and in debts, my dog got some disease from ticks, parvovirus and etc. so the next three months that I was supposed to have side effects, I don't know if I did. I've had bad moods...I've been buried in alcohol, not going out anywhere, isolated in the house...I have depressive tendencies anyway...so I don't know if I've had side effects or not. The side effects that could have occurred were an upset stomach which happens because of alcohol...getting excessively fat, but because for three months I hadn't eaten anything, I had lost weight...the double nape that I felt, but I don't know if it was because of the treatment or because after I got a job, I started coming back to life, I started eating and my body started depositing fat." (M, 34, MSM)

"Well I don't know about that, but basically, I don't think so, I mean everything I had was on a psychological level, but it didn't feel physical so to speak. I generally have a healthier frame, which is probably why my high immunity has kept me so strong. So no, on a physical level, no, but really psychologically I've suffered depression...whatever...I've been through a lot. Depression, that is. But things happened...eventually, my ex-husband and I divorced...there were several events..." (F, 36, HS)

1.3 Viremia monitoring

1.
Individual level

THE RELATIONSHIP WITH THE DISEASE
Viremia monitoring

Do you monitor your viremia? How frequently? Was it detectable at the last monitoring?

According to the National Strategic HIV/AIDS Plan 2019-2021,[22] 100% of people living with HIV/AIDS in active care should have access to biological monitoring (viremia, CD4), including those belonging to priority groups. Of the people living with HIV interviewed, only one person did not confirm access to follow-up testing. It is about an injecting drug user (therefore from a priority group) who at the time of the study had been in treatment for more than 6 months and had not yet managed to benefit from periodic testing, because "the hospital did not want to test me, ... because the laboratory doesn't have I don't know what".

> "Yes, the last viremia I remember is also from prison around 2017 I think, and I had 50,000 virus replicates. [...] Yeah, it's done for free...of course the hospital has to do it for free. But the hospital I'm at, Victor Babes, wouldn't do it to me. I don't know what the issue is, they did it for other people, but the doctor told me that it was not possible, that it didn't work, that the laboratory didn't have I don't know what ... I kept insisting to have my viremia tested and now again I was told that they couldn't do the viremia, that they didn't work, that the laboratory didn't have ... I started treatment that way and (CD4) my immunity increased. Eventually I went to a private clinic and did it myself when I saw that there was no other way, I was curious for myself. In November (2019) I had it done and found I was undetectable." (M, 34, HS, IDU)

The other 3 people who had started treatment less than 6 months at the time of the study were tested every 3-4 months, did not expect future problems with viremia monitoring and reported positive results.

> "The viremia at the beginning was 62,500, after four months it reached 550, CD4 37, it jumped to 192. And this one (the doctor) freaked out, how well you're doing, how cool ... yes, I also changed my diet, I no longer eat fried food ... although I can eat anything on HIV treatment, you have no restrictions...except certain spices, but otherwise I can eat anything. He also tested me for hepatitis, I didn't have any hepatitis, I didn't have EpsteinBarr, I didn't have any these HIV-related infections, I didn't. Apart from syphilis which is curable." (M, 42, HS)

Of the 15 people who at the time of the study had started treatment more than 6 months ago, 12 monitor their viremia on time, some (2) even additionally (every 2-3 months) pay for testing at private clinics. With one exception, all of these people in the sample report undetectable viremia, although in some cases CD4 (immunity) is still at a relatively low level or growing very slowly. The exception case concerns a person who had a relatively low (but detectable) viremia level at the last follow-up because "I skipped a dose or two. I kept having urinary infections and I had a fever of 40 and I couldn't swallow anything and I was already taking fever pills, so I didn't follow the treatment properly" (F, 32, HS)

[22] Ministry of Health (2018) http://www.ms.ro/wp-content/uploads/2018/11/Anexa-la-HG-Plan-National-HIV-2019-2021.pdf

"Well, every six months I've had it done so far, except last fall I had it done myself at a private clinic. I wanted to know if I'm getting to undetectable... Doctors look for CD4 levels rather than viremia. For example, my CD4 was rising steadily, but I was not going undetectable. And my doctor was very happy that my CD4 was rising and I was really sad that I wasn't getting to undetectable. That I felt safer for others. For me it was very important to get to undetectable because it made me feel less dangerous. And at the last monitoring it was undetectable." (M, 42, MSM)

"I would monitor it (viremia) every 3 months, as it used to be, but I do it every 6 months because there are no funds (reimbursed by the national Health Insurance Company). Given that, and here the doctors are right, an undetectable infectious viremia does not change from one month to the next. I went in July, now I'm scheduled in March, because some funding came in and they said they hadn't tested me in so long and called me to have it checked again." (M, 27, MSM)

In contrast, 3 people (out of 15), although they have access, claim that they do not monitor their viremia on time, because they either "have never done it" (and do not know their viremia) or "are too fed up with the reactions and the way things work in the adult ward", all the more as they are "already undetectable for years".

"Because of my job ... I couldn't get there once every 6 or 3 months, I managed to get there once a year. Now sadly I think it's been a year, a year or so since I've had a viremia test. And this is strictly from the doctors' perspective, because I admit [...] that I don't want to, I don't feel like going to the doctor because I'm too fed up with their reactions and the way things work in the adult ward. But I have to do it." (F, 30, HS)

1.4 The perceived impact of the disease

1.
Individual level

THE RELATIONSHIP WITH THE DISEASE
The perceived impact of the disease

Do you feel affected by the diagnosis? Which contexts do you feel most comfortable in?

Few of the interviewees living with HIV/AIDS explained how they were affected by their diagnosis and in what contexts they felt it most. However, most of these are people who are not in a stable relationship (as opposed to those who are in a couple, whether HIV or serodiscordant). Loneliness and an "inner fear" that they might infect other people are most commonly mentioned. The process of informing the family (parents) is described as difficult and, in several cases, lengthy. The process of building a stable couple relationship is also perceived to be difficult.

"In the beginning it was hard, a few years...it took a while. Especially since you can't tell those close to you, I didn't have the courage at the time to say. There was this thing...because I knew it would affect them or...not judgmental...no, not in that form...but then I got used to it and it was ok. [...] When I had my diagnosis I was about to get married. Indeed, there is still this fear...there is an inner fear. Wait a minute, it doesn't go sway it's there...even if you can't see it...it's there. I can ruin a life... in my mind. That's why there are only purely physical relationships, so to speak." (M, 44, HS)

"It becomes a habit over time, but sometimes you feel bound and... like handcuffed. And of course, you feel somehow that you are not the same as before and no longer have the freedom and opportunity to create a relationship without problems. Because many people do indeed shy away from HIV-positive people. Otherwise, I'm personally very OK, I have moments when I'm sad and upset that it happened to me, but I prefer not to think about it and go on knowing exactly what I have to do and following directions." (M, 42, MSM)

"I resent it most in the evening when I have to take the pills because I know I have to take them for the rest of my life. And in the past (before I was in a couple), I used to experience loneliness...when I would talk to girls and get to a point where we could move on and I would realize...wait you have HIV...I had to stop...from the relationships viewpoint." (M, 34, HS)

"To be honest, yes, I feel affected by this diagnosis. The moment I meet new people, online I mean or even face to face, at the bar or in the club, who are interested in getting to know each other better...from a simple sex date to something serious...and you have to say this stuff. It is the most or one of the nastiest, even awful moments you can have carrying this diagnosis. It's actually terrifying. Terrifying. [...] So when you have to tell a person with whom you possibly have an intimate relationship it's awful. It's awful because most of the time the reaction is negative, it's 'block' all the way, it's gossip, it's discussion, more and more people find out, you're pointed at, you're discriminated against." (M, 37, MSM)

Other interviewees talk about co-infections, for which it is difficult to find medication that does not interact with ARV treatment, or about complications of providing treatment in the context of activities such as travelling for longer periods.

On the positive side, there is one interviewee who says she feels "privileged" because her diagnosis gives her access to a regular minimum income, which she could not get before her diagnosis.

"I feel privileged because I used to have this fear about losing my job. I had to have a job and I could only find low paid jobs at some point and I got angry...I said, look, I can do a lot of things and look how bad the wages are in Romania. So the fact that I have a minimum income... And now I want to get the right to work, to be able to work. I really want to work. I'm very active...I've always done a lot of sports. Yes, and I don't necessarily feel affected because now people know I'm a quality person and they want to work with me, they don't discriminate against me. I'm not unfit." (F, 31, HS)

1.5 Perceptions of HIV before and after diagnosis

1.
Individual level

LIVING WITH HIV IN ROMANIA
Perceptions of HIV before and after diagnosis

Tell me, has your perception of HIV changed in any way? Before diagnosis and after? How?

Questions about how perceptions of HIV changed before and after diagnosis do not apply to people (4) who were infected and learned about it as children. They have lived with HIV all their adult lives. Thus, out of the total sample, 15 people answered the questions in this section, people who were infected as

children or adults but learned their diagnosis as adults.[23] The analysis shows that perceptions of HIV change over time under the influence of two main factors: (i) how the infection occurred - as a result of assumed risk-taking behavior versus inappropriate behaviors of others (including in childhood) and (ii) the time since diagnosis. How perceptions change after diagnosis according to these two factors is shown in the figures below.

GROUP 1: Diagnosis as an adult, unassumed risk (dentist, hospital, abuse)

(5 people in the sample)

BEFORE	DIAGNOSIS	AFTER
		Stages ordered by length of time since treatment began (from under 12 months to 20 years)
They had no information on HIV **They had never thought that they could get the infection** **Negative stereotypes** "Oh my gosh, when I used to hear the word HIV, it was horror...there was a rumor that they were injecting HIV into bananas, into food. Oh ... my, I say, this is as far as it has gone...and that they inject HIV mostly into vaccines in schools. [...] I heard it too, what a horror, what a society, what a world ... they are destroying people with HIV" (F, 31, HS)		**The initial shock** "And when I heard HIV/AIDS, death. [...] That's why I burst out crying, I say mom my life is over, I'm so young and I haven't got to do as much as I want to do." (F, 31, HS) **"Why me?", anger** "I can't say I've come to terms with my diagnosis. I mean, to be honest, I still have times when I'm angry about it, I admit it." (F, 36, HS) **Learning about HIV and finding out there is a treatment for it** "But then when I saw that there's treatment and you live well just by taking the treatment, living as healthy a lifestyle as possible...so I'm very optimistic." (F, 31, HS) **Coming to terms with it, resignation** "I'm super grateful to finally be allowed to listen only to my soul." (F, 31, HS) "I have to live. I thought I had to live for my daughter, I wanted to see her settle down." (M, 32, HS)

[23] Two people who were infected as children but did not find out they were living with HIV until they were 23 and 28, respectively, responded.

GROUP 2: Assumed risk (unprotected sexual intercourse, injecting drug use)

(10 people in the sample)

BEFORE DIAGNOSIS	AFTER
	Stages ordered by length of time since treatment began (from under 12 months to 20 years)
They had information on HIV and were aware of the risk of infection **Some had friends living with HIV** **But, they were indifferent to HIV, "I didn't care"** "Because even before I knew exactly what HIV meant and I didn't have any kind of negative reaction towards HIV positive people. I had HIV-positive friends for many years before I got infected myself, and I treated them as if that HIV didn't practically exist, I didn't care." (M, 42, MSM)	**Adjustment (starting life with HIV)** " This is it, if I'm positive...it's not the end of the world." (M, 34, MSM) **"Why me?", anger** "I think the more difficult question is why me." And I think that's what everyone have asked themselves. I just got away without a condom in a relationship." (M, 34, MSM) "... however, you think about it and then you get the urge to bang your head against the wall. It also irritates me when I'm alone and when I'm having a Colentina-type conversation...yeah, naturally, that's when I rant. And I'm taking it out on others, slamming, bursting...and I have two puppies, the only things that calm me down." (M, 56, MSM) **Learning about new treatments and the national program** "Now I know what this is about. I know what it (HIV) does, how it works, but to me it doesn't seem like such a hard thing because I've caught up with these better times with fewer pills. There are guys in the group who used to take 16 pills a day and all kinds of injections." (M, 34, HS, IDU) "State institutions have only started to get more involved in this direction in the last ten years...before that ... God have mercy." (M, 34, MSM) **Resignation** "And that guy asked me if I thought HIV was visible and it's still okay and you can have sex without a condom, if you have HIV what are you going to do? And again, I don't like to lie so I was very direct and told him I was going to look for the highest building and learn to fly. And look at me eight years later not climbing the highest building. Okay, I've been in the deep end, clearly. Almost three years, but I'm finding a way to somehow pull it off. My perception is... I don't know... I can live healthy until I'm 80 if I follow some basic conditions. Anyone can live, if a brick doesn't fall on their head." (M, 34, MSM)

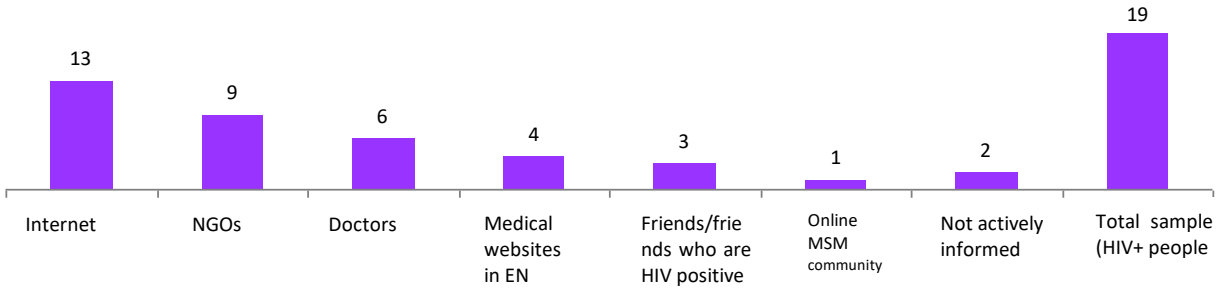
1.6 Sources of information on the disease

1.
Individual level

THE RELATIONSHIP WITH THE DISEASE
Sources of information
What are your main sources of information on the disease and treatment?

Out of the total sample of (19) people living with HIV, only 2 interviewees stated that "I don't spend my time looking for information, if something comes up it comes up" or "the doctor tells me".[24] The remaining (17) people stated that they actively and regularly inform themselves to find out relevant news especially regarding treatment. Importantly, sources of information do not differ by gender, education level, living in a couple (versus not in a steady relationship), sexual orientation (HS versus MSM), mode of infection, nor length of time since starting treatment (from a few months to 20 years).

Figure 3. The main sources of information on HIV and HIV/AIDS treatment



The main source of information for most interviewees (13) is the Internet. Some of them (4) say that they do not go on random pages, but follow a number of English-language specialist sites that provide "solid and up-to-date" information.

> "A couple of months after I also had the talk with my wonderful doctor, I went on the Internet and the Internet ... And when you go to Babeș Hospital, there are all sorts of posters telling you the websites...you have to take a picture, remember or go in at once. But I think 90% of the good sites were in English. And there were so many terms that at one of the sites I had to do the translation myself ... go somewhere else to find out ... and that 'undetectable', 'equal', 'untransmissible' stuff. For me it's ok, I understand, I can manage. But they are not for everyone. Difficult to read, to make the right selection, to understand." (M, 34, MSM)

The second most popular source of information refers to the services and activities carried out by NGOs, such as UNOPA,[25] ARAS or Sens Pozitiv.[26] Nine HIV+ respondents mentioned: (i) NGO representatives providing them with information, along with counselling or support in different situations; (ii) brochures

[24] (F, 32, HS) and (M, 27, MSM).

[25] The National Union of Organizations of People Living with HIV/AIDS; https://unopa.ro/

[26] The fact that these NGOs were mentioned is a sampling effect.

and other information materials, including sent by email; (iii) training activities or support groups. Through these activities, interviewees not only learned useful information, but also received advice or support in different situations and, most importantly, "made new friends".

> "Now I'm going to a support group, that's how I found out about you guys at UNOPA. I learned a lot of things there and I'm still learning. Even tomorrow there is a group meeting...so from them too...I even learned things you don't find on the Internet: life situations they've encountered, for example, discrimination at the dentistry...which is unfair...because you can have HIV and not know, they are forced to sterilize anyway." (F, 31, HS)

> "My most important source of information is the NGOs that deal with this...because these NGOs update this database almost every day, plus I have made new friends." (M, 34, MSM)

> "Before, I couldn't get my information from anywhere. Because I wasn't interested. Until two friends suggested that we go to the group, as they were taking about this situation, about certain things..." you'll learn new things and you'll like it". Now I joined this group at UNOPA, every Friday we get together and talk about this situation. And I learn new things that I really didn't know, even though they are old and ancient. And I didn't know them at all. And I've been going for a couple of months and I really like it." (M, 32, HS)

The third source of information, mentioned by only 6 of the 19 HIV+ participants, refers to doctors/hospitals. The mentions are of two opposite types. On the one hand, there are people who do not have a good relationship with a doctor (be it the attending physician, the family doctor or others) and who point out that they turn to the Internet and NGOs precisely because they do not receive information and advice from the doctor/hospital. "With our doctors it is very difficult to have a discussion with many questions" says (M, 34, HS, IDU). Or, "I turn to NGOs or on the Internet, because now I'm much more informed, because at the hospital you don't, you don't have any counselling, no chance" explains (F, 36, HS).

> "When I was telling you that he (my partner) got sick and I asked the doctor. And he shrugged her shoulders: do as you think...madam, this is not a doctor's answer...why should I interfere in your household?! Madam, I am not telling you to interfere in my household, but simply to tell me what I can do. And she didn't tell me. And then I started to do it myself, I did nothing but browse, let's say it frankly, the Internet pages, and I tried to see what I had to do and how to do it." (M, 56, MSM)

On the other hand, in opposition, there are people who have found "wonderful", "extraordinary" doctors (either their attending physician, the family doctor or various doctors from other specialties) whom they consider key to their well-being, not only because they prescribe effective treatment, but also because they explain, inform and advise them.

> "My doctor in Ploiești, the attending physician, is an exceptional woman, I have confidence in her and if I have a toothache I still go to her. When my mother was sick, she had pneumonia, we trusted her the most." (F, 31, HS)

> "And really whatever curiosity I had and whatever questions I had to ask, I talked to the doctor and she explained them to me...really very OK. I mean in the limited time she had, she gave me all the necessary explanations. She didn't send me away, she didn't rush me, she was OK. I am no longer with that doctor now because they moved the infectious ward to Central Military Hospital and now I am with another doctor with whom I have not had so much interaction. We have to understand them too that there are few of them and many patients, and with a man like me who is an informed and medically trained man it is very easy to talk and they probably expect me to ask some pertinent questions to be answered, they don't need to explain things through, because they know I already know." (M, 37, MSM)

> "They sent me from Ploiești, from the infectious diseases hospital in Ploiești, they sent me to Bucharest, they gave me a letter of referral to Matei Balș, I was lucky, thank God, I met a very good doctor, very young, respectful, everything you could want from a practical doctor. And he said don't go and get the CD4 tested at Synevo, when you feel like it, call me and I'll give you a referral and you can do it for free here, because it's more expensive ...it's about 300 RON. [...] What an extraordinary man, my God. A self-taught person and everything you could want from a teacher, and I say I learned about this HIV infection from you, I am a little closer to becoming a virologist...what a virus is, what a bacterium is." (M, 42, HS)

A small proportion of interviewees (4) said that they get information from friends/pals/other HIV-positive people who were infected several years ago and know more. This type of behavior, at least in this sample, seems specific to MSM individuals.

> "And then I created a fake profile on one of the gay apps where I wrote that I had HIV and asked for information. A surprising number of people wrote to me. Somewhere between 20 and 30 people, with whom for three, four, five months, I talked as actively as I could, whenever I could, to find out different options, different things. I've always liked doing research. So somehow, I put all the information together...I've heard very sad cases. I kept in touch with a few people and discovered that we knew each other. And there's still respect with those people, we talk, we laugh..." (M, 34, MSM)

Finally, at the sample level, people fall into three roughly equal groups in terms of the number of main sources they use for information: 5 people - 1 source; 6 people - 2 sources; 6 people - 3 or more sources. Most of the people who use a single source of information are beneficiaries of services provided by NGOs, which indicates that NGOs succeed in attracting precisely from the pool of people living with HIV who would not otherwise be informed.

> "For information, no, I didn't go to the foundation (UNOPA). I got the information, let's say online, from the foundation or more precisely from these companies, there are several that deal with this. And I also looked at international studies also online, so from the medical area, official studies, WHO (i.e. World Health Organization) working on this area, not others. And the doctor told me that there might be something, I mean I keep in touch with him and he's ok from that point of view. And the family doctor, my dermatologist is also interested...the doctor who takes an interest in my condition and comes up with concrete and correct answers." (M, 44, HS)

2. Family and personal relationships

2.1 Disclosing and hiding the diagnosis

2.
Interpersonal level

LIVING WITH HIV IN ROMANIA
Disclosing/hiding the diagnosis

Disclosure of diagnosis - Does anyone other than yourself know your diagnosis (current or former partners, family members, relatives, friends, colleagues, family doctor, dentist, etc.)?

Hiding the diagnosis - There have been situations where you have had to hide your diagnosis. Why?

Disclosing the diagnosis

The sample includes 19 HIV-infected people who choose to disclose their diagnosis. However, the distribution of diagnostic confession behavior makes distinctions in terms of manner, recipients, and rationale for disclosure.

First, a distinction is made between selective and open ways of disclosing the diagnosis. The selective manner (10 people) involves choosing the recipient on the basis of a high degree of privacy, excluding disclosure to acquaintances and strangers. By comparison, the open manner (9 people) involves disclosing the diagnosis both to recipients in their private sphere and to acquaintances/colleagues at work - including declaring the diagnosis in public/online spaces such as Facebook, forums, in social campaigns or on dating pages/apps.

In terms of recipients, four types are identified - friends, family (which includes partners, parents, siblings), managers/bosses/work colleagues[27] and support groups[28]. Predominantly, after diagnosis, people with HIV/AIDS initially confide in friends. Then they go on to reveal the diagnosis to family members, colleagues and so on. Exceptions are people infected in childhood and people, at the time of diagnosis, living in a couple who initially choose (or are forced) to confess to their family/partners. However, for most, the recipients are easily enumerated, often less than 5 recipients per HIV-infected person.

Three categories of diagnostic disclosure rationale are observed. The majority (10 people) confess their diagnosis to friends and family. This category shows a propensity for open manner, indicating a certain lack of reluctance to declare an HIV/AIDS diagnosis. Only 3 people[29] keep the diagnosis in the family, which seems to be characteristic of those infected in childhood. This category shows a predisposition for the selective manner and tends to be the most affected by the diagnosis, expressing not only reluctance but also a desire to avoid confessing the "stigma-causing" diagnosis.

> "- *When you were first diagnosed, who did you talk to?* It was my husband who... it was then when he found out too... *But who else did you talk to?* No, so I didn't talk to anyone...that was a problem then that I didn't ask

[27] This category of recipients is discussed in section 2.4 Discrimination and stigmatization.

[28] One case in the sample (M, 34, MSM).

[29] (F, 31, HS), (M, 34, HS, IDU) and (F, 36, HS).

anyone for specialist help and that was it. I didn't even inform myself on the Internet...I mean at that time I lived in total indifference. So, I haven't talked to anyone specialized. *What about your family? Colleagues at work, at school...?* I had all the prejudices. I didn't accept it, I couldn't...I just totally refused it...I just put it away in a corner of my mind and that was it. And the family...even though supportive and so, but they didn't react too well either, it took them a while to adjust. Whatever...we live together and when they found out, they all got tested, I didn't...I don't know what...whatever...well in the meantime they got it together...and yes, there was this problem with the stigma that I couldn't tell anyone outside the family. And that's the problem I'm having right now...with my job...but I'll tell you about it when we get there. So, I after I divorced him...so we found out in 2012, later by 2014 I think we got divorced, somewhere around 2015 I ended up in counseling, seeing a psychologist from totally different happenings, but good thing I did. That's when I started to see life differently." (F, 36, HS)

The remaining (6) HIV-infected people only confessed to friends. This category shows a predisposition for the selective manner, it tends to be male-specific, expressing reluctance to avoid difficult situations with high emotional load for both themselves and their parents.

"Related to the disclosure of your diagnosis, apart from you, does anyone else know the diagnosis? Some friends and my boss know. What about family members, don't they know? No. *Why didn't you have the openness to share your diagnosis with family members?* Well, I could just tell my mom, but that would complicate things and create a lot of problems. As my mother is an older woman, I don't know what she would do. She wouldn't understand, she'd freak out, she'd panic. I don't need that. I need peace and quiet. On the other hand, I would suffer extra and that's not the case." (M, 42, MSM)

"I'm managing the situation...I can't tell my mother because she would be scared, I'm afraid of her reaction. I didn't even tell my sister, I only told a friend. But I warned him that if he told anyone, he'll be doomed. Because I told you privately and I told you, don't tell anyone, what we talk about, it stays between us that way. *But you didn't tell your family for fear of the pressure you put on them?* Yes, I was afraid. They don't live in Romania. Here's the problem. They got me a house, I have my own house. They don't live in Romania. And it would have been too much of a shock and for now if I'm doing well with the treatment, albeit a mild treatment, but still giving me some trouble. Anyway..." (M, 42, HS)

At the sample level, there appear to be differences in diagnostic disclosure between HIV-infected people living alone and those living in couples. More specifically, the singles group tends to gather individuals who prefer the selective manner and who choose friends as their sole recipients.

People infected with HIV as children have lived with the diagnosis for a long time. Thus, they tend to be pragmatic when it comes to disclosing their diagnosis, preferring the open manner – only one in 6 express reluctance to do so.

"Does anyone besides you know your diagnosis? My godparents know, yes, I don't shy away. I don't have any problem with them finding out...so I take care that people who might affect the children at school, at kindergarten don't find out. That is all. Otherwise I really don't care. They can find out. If they want to talk to me fine, if not... it doesn't affect me anymore. It used to affect me a lot. Now I have no stress about it." (F, 32, HS)

Compared to men, HIV-infected women prefer the private way and choose - in particular - family as recipients of disclosure. Finally, no differences in diagnostic disclosure are observed between heterosexual and MSM individuals.

Hiding the diagnosis

The majority of respondents (16 people) choose the behavior of hiding the diagnosis. For people living with HIV/AIDS, both the diagnosis itself and its disclosure is a difficult and lengthy process. Moreover, disclosure can lead to negative events in their lives and those of their families. Thus, there is no narrative that does not mention at least one of the following negative consequences associated with an HIV diagnosis: discrimination, fear, shame, isolation or depression.

Therefore, this section focuses on the behavior of using diagnosis as a relationship between disclosure and concealment, from which the following behavioral typology emerges:

- STRATEGIC behavior - "Yes, I disclosed and yes, I hid the diagnosis". The category includes 8 people in the sample.

These people tend to choose between disclosing and hiding depending on the purpose of the interaction. They pursue not only their interest but also their right to privacy (including confidentiality of diagnosis). The majority (5 people) do not shy away from confessing the diagnosis, indicating a high degree of acceptance of the diagnosis.

> "- *Was it ever necessary to hide your diagnosis?* Yes, at first. When I wasn't telling anyone... And now I was in a camp and I didn't tell my classmates that it wasn't the time to tell them...they would have discriminated against me anyway. *Were you afraid of that?* Yes. At least one, two, would have discriminated against me." (F, 31, HS living with HIV for 4 years)

The strategic behavior is based on cost/benefit decisions. Specifically, it appears to be characteristic of women living in couples, MSM living alone, and people infected with HIV as children, regardless of whether they learnt their diagnosis at a later stage.

- CAUTIOUS behavior - "I did not disclose and yes, I hid the diagnosis". The category includes 8 people in the sample.

This category is dominated by men living alone, heterosexual, infected with HIV as adults and with assumed risk. The data suggest that this behavior would be characteristic of people still in their early years after HIV diagnosis. However, this category can also include people who have been living with the diagnosis for a long time.

> *" Has there been a situation where you had to hide your diagnosis?* For example, at home, in the country, I was at one time very cold and it caught me when I was in the country, the cold. And I was very, very, very sick. Now, well, my mother knowing me as well as she did, she realized something was wrong, she saw me at one point taking some pills. What pills are those? Some vitamins...but what vitamins, so we can give them to your father, they might be good. Ah, no mom, they're not for dad because you know he has high blood pressure, they're not for you either, don't worry. But let me see them. Here, let me show you. Stuff like that, you know? Then I had to be even more careful and if my mother noticed, it would be cruel for my sister to notice. That's pretty much it. There are other situations, because well, we all have all sorts of people around us and there are some loudmouths that you can't expel from your life just like that anyway because retaliation follows. Then you have to shut up and suck it up in certain situations when this comes up. When it comes to this stuff you have to shut up and suck it up or... if you're prepared enough at the time, take it on and speak up, take the bull by the horns and so on. I did the thing. *So? Did you get any results?* Neither of them is a solution. Keeping quiet is not a

solution, nor is...it depends on the person and there is really nothing you can do about it for some people. No way. Neither good nor evil." (M, 37, MSM living with HIV for 3 years)

"Have you ever encountered discriminatory attitudes? Personally, I haven't. But precisely because of this, the entourage, friends, pals, acquaintances don's know about this problem either because I'm afraid of discrimination...only my family know, that's all." (F, 31, HS living with HIV for 11 years).

The narratives of people in this category can be interpreted as mirrors of a merciless exterior, where 'others' will not understand, accept or tolerate them. Their behaviors seem to involve social isolation, self-distrust and to be driven by fear/shame.

- CATEGORICAL behavior - "Yes, I disclosed and did not hide the diagnosis". The category includes 3 people in the sample.

With the exception of male prevalence, other socio-demographic characteristics cannot be extrapolated due to low numbers. But these people seem to choose between revealing and hiding based on a personal value system - their behavior is the result of internal decision-making processes rather than a reflection of the outside.

"*Have there been situations where you had to hide your diagnosis?* I really don't remember. Well if I go to a job I don't really say so you know...I have HIV, come on, will you hire me? I mean I don't reveal like this, we have to get closer, have a friendly relationship. Who knows unless it's such a context, because I'm not going to do it just like that. I have no problem whether anyone knows about me or not. I don't feel lower or I don't know how that I have and the others don't. I don't want to set limits or barriers for myself, you know I have HIV, I can't do what someone else does. And that's also due to the fact that I really did inform myself quite a lot. I've always enjoyed facing obstacles like that and with each obstacle I've overcome, I've gained more confidence in myself." (M, 32, HS living with HIV for 30 years)

Overall, the majority of HIV-infected people actively (currently continuously) use one of the three disclosure/hiding behaviors. However, 3 people in the sample talk about hiding the diagnosis as a fact of the past, indicating some detachment from the reactions or consequences of disclosing the diagnosis.

" Many years ago, I was working at an educational center, working with children. I've been training for as long as I can remember. With kids, with young people...that was the only job I didn't tell them, I don't know why. That was the only place." (F, 30, HS)

Disclosure/concealment behavior also seems to be predominantly used in the following social situations: friends (especially towards those who are or might be in a sexual relationship), the workplace and the medical system. The experiences of people living with HIV in the healthcare system in Romania are discussed in detail in section 4.2.

2.2 Couple relationship/serodiscordant couple experiences

2.
Interpersonal level

HIV/AIDS DIAGNOSIS AND THE COUPLE RELATIONSHIP

Couple relationship/serodiscordant couple experiences

The extent to which the HIV diagnosis has affected the couple's relationship. Does your HIV-positive diagnosis precede your current relationship? If so, how did you come to discuss this with your partner?

Serodiscordant couples and the opinion of HIV- partners

The desire to have a family (children)

Regardless of when they were infected, even if temporarily, the HIV+ diagnosis negatively affected the person from the perspective of loving relationships. For those who were infected as children, this meant multiple experiences of rejection. For those who were in a couple at the time of diagnosis, the main consequence was the end of the relationship. People living with HIV tend to talk about previous romantic relationships as traumatic events, situations in which they were humiliated and misunderstood. As a result, HIV+ people tend to readjust their behavior to disclose/conceal their diagnosis.

> "Do you know what my biggest dilemma is? I've been single for three years since he left me. My biggest dilemma is: when is the right time to tell a guy this. No, there's no good time... *There isn't?* I tried it with a guy, see each other for a long time to get to know who I am as a man without doing anything sexual, not even holding hands and when I felt it was time to tell him. The first thing was, oh, God I held your hand. A guy who is the brand manager at a very big company in Romania. Who clearly is educated but... I tried to say it the first time. *And?* No, it doesn't work. See where the door is? No, it doesn't work. I've had two attempts at a relationship with two guys I told from the beginning, but somehow, they felt it. They acted like staying was the most important thing in life and they stepped on my head. I mean, they felt the need to... And I want someone balanced who understands the context. Because if we were to be one hundred percent honest, it's much safer and it's recognized by a million studies [...] it's *safer* to fuck someone or be with someone who is undetectable and who is on treatment. So, someone who clearly knows their sexual and health status better than anyone else." (M, 34, MSM)

In addition, there are instances where the HIV+ person can self-sabotage and self-exclude themselves from the love life.

> *"How has it been being in a relationship with your partners throughout your life?* Well, maybe I was lucky or maybe I don't know. I started my sex life quite late, when I was 20. So, I didn't have this problem from age 11 to 20 to say okay, now what do I do, what do I call it or whatever. Instead, in my mind, psychologically, I was somehow... why would I be in a relationship, no one would accept to be in a relationship with me. I had a relationship, I was 15 I think, my first relationship, but it lasted a month and nothing happened and that was it. And the rest of what they were, they weren't actually relationships because they weren't... But in my mind, that's what it was, and somehow the barriers I was putting up were just from this perspective that no one would accept me with HIV." (F, 30, HS)

People living with HIV who are not in a stable relationship are either searching, focused on other dimensions of life (e.g. career) or still have difficulties with "normalizing" their medical condition in their

daily lives. Furthermore, these individuals tend to still be in their first 5 years after diagnosis, are male, and they prefer the cautious behavior of disclosing/concealing their diagnosis. However, most people who do not live in a couple consciously choose this lifestyle.

> *"You said you're not in a relationship at the moment. Is it difficult for you, does it affect you in finding a partner or maintaining a relationship?* It has never affected me in finding a partner. All the partners I had after the diagnosis were negative. Everyone knew about me, they understood what it was about. With some people it was a little harder to understand the dynamics, but slowly, slowly they understood. And they become aware that you don't want to harm them. They gain confidence, because when you have the courage to say these things up front, you become a person of great integrity. It hasn't stopped me from continuing my relationship, the fact that we separated was for other reasons. There have been people who, although they are hypochondriacs, cannot mentally overcome this, preferring not to know rather than to know." (M, 27, MSM)

> "I would like a partner who understands first and foremost that whether she is living or not living with HIV, it doesn't matter. It only matters that she understands, that she doesn't look after that... but I haven't had the time during this period to have a stable partnership. I haven't had any real time, I'm trying to move on with my life." (M, 44, HS)

Life as a couple HIV +/+

Of the 19 people diagnosed with HIV, 8 live in couples. Life in couples seems to be characteristic of women and MSM, predominantly infected in childhood; who are not differentiated by the manner of disclosure, for whom the family is the main recipient and who prefer the strategic behavior of disclosing/hiding the diagnosis.

For HIV-positive couples, whether heterosexual or MSM, the choice of partner seems to be conditioned by the HIV diagnosis. In other words, most prefer to choose partners who also have the virus, both to avoid difficult situations of rejection/inhibition/fear, and to avoid the guilt or responsibility of potentially infecting the partner (who is not sick).

> "*But have you met in a disease-related context?* It mattered, I mean it was fifty-fifty, as, because I was sick I wouldn't have been willing to get into a relationship with a man who isn't sick. So that was one criterion, but not the first. [...]From my point of view it's simpler. But not necessarily as a sexuality relationship, but in terms of mentalities. I don't know, we don't have a problem with that. Our main concern about the disease is taking our medication. I'm like this, I'm careful that he takes his meds, I'm careful that I take my meds, and that's pretty much the only worry." (F, 36, HS)

> "In 2016 when my results came back, we went to my GP, where he also goes, and I told him here's the deal: as of today, we are ending the relationship. I told him straight out. Something doesn't smell right. You're seronegative, you get tested too, if it's seronegative we're through. I don't want you to get in trouble because of me. Oh, my. As I am a “clear cut” Cancer, he wouldn’t hear about it. 'What?! Throw away 2012, 2013, 2014, 2015, no way!" he said. 'Show me those'. I showed them to him, he saw that it was true. And he said to me: 'No problem, I'll do the test too, if we're both HIV positive like you are, no problem. We know where it happened, we know the thing broke back then. And it's good that you told me in 2011 when your boyfriend told you, I was expecting it, I don't understand why you want to break it off'. And God forbid, I want to do it without protection because I have a latex allergy, it totally irritates me. If I want to do it without protection, what do we do in that case, I asked. Especially since I'm still detectable. Only when I'm undetectable, both you and I, will there be no risk. We went to a bar we got drunk despite our illness. We got so drunk we couldn't stand up. We went home, we recovered the next day, with pickles, with sauerkraut, with all kinds of crazy stuff... he says 'where are the results, let's make some copies', we kept the originals, we put them in a file and he took the copies, tore them up and said 'nothing happened'. What a great time that was. For me it was a golden moment. And since then we have stayed together. His CD4 is 1300 something and mine is 625. A bit

bigger than mine because I don't know how he does it, I think he eats a lot of these bio things from the country. Well, he knows." (M, 34, MSM)

When it comes to finding a partner, heterosexual HIV+ people tend to opt for online dating sites that cater only to HIV-positive people - which offer a non-judgmental space where they can find partners they understand and are comfortable with.

Life as an HIV +/-

In serodiscordant couples (3 cases in the sample), the dynamics between positive and negative partners focuses predominantly on protective measures and risk-taking. Partners (2 people in the sample) who do not have the disease tend to be informed about the HIV/AIDS condition and are aware of the implicit risks of being in a romantic relationship with an HIV+ person.

> "Then I found out about some controversies that didn't convince me and I was somewhat in doubt. I was also in doubt as to whether there had somehow been an error in diagnosis. Because the tests were at one time positive than negative, very suspicious from my perspective. As I got to know her more closely, I realized that she was a more sensitive nature who may have had some diagnoses and disorders on somatic causes and I thought that would be the most. I thought this was the least likely and maybe there was something wrong and there are mysterious ways in which the immune system and the body work and no consistent diagnosis has been made. Although the symptoms were multiple. There are a lot of issues at stake in reality about this HIV thing. I've done some research myself, I'm not a doctor, but I've done some research as a result of being associated with someone like that. I have researched the controversies, the issues, including doctors from various camps and I have no idea what the truth is. But the truth is somewhere in between. And especially in this case. It's strange, but things are going well and that finally convinced me." (M, 32, HS, HIV- partner in serodiscordant couple)

Moreover, serodiscordant partners tend to express a need to accept and support their HIV+ partner, believing there is no difference in terms of the demands of the love relationship.

> *"What does it mean to be a partner in a serodiscordant couple?* So that means being careful with yourself and your partner, for your health eventually. Second to none, be careful to try to help your partner overcome their problem in ways you understand, because you can't do more than you understand to do. Unless it's a happy accident, so at the same time you have to be understanding, to morally support the person in question, concretely through physical exercise, by trying to discover maybe new ways of informing yourself in this sense of adjuvant therapy in these cases." (M, 30, HS, HIV- partner in a serodiscordant couple)

However, there are instances where the hesitancy, fear and immaturity of the discordant partner can affect the emotional well-being, life plans and self-worth of the HIV-infected person.

> *"Do you find that your HIV status affects your relationship in any way?* Yes, he [*the partner is serodiscordant*] is very paranoid. I told him I was undetectable and that I wanted him to get tested for HIV. I have told him that I want a family, I want children. It's important for me to get all the tests, not just the HIV test. He says he wants to hang out with others while he's with me, that he hasn't experienced enough sex and I told him he could experiment with me. At least please me. And he's very unbalanced. I'm considering whether to continue my relationship with him or not because I don't really like his instability. Today he loves me, tomorrow he is with others. He doesn't want to do the tests, he wouldn't find a job." (F, 31, HS)

The desire to start a family (children)

Most HIV-positive people living in couples have children or are considering having children. Regardless of whether or not they were in a serious relationship, all women dealt with the choice to have children

considering their current age, the impact of their HIV diagnosis (effects of medication, poor physical condition - lack of energy) and the potential infection of the child.

> "I mean, I can be as energetic as person who's energetic in their own way, or I can be tired, because I have days and days. Instead, maybe it would be this getting pregnant thing. Something I'm not ready for and I don't know if I'll ever be ready to do. [...] you live for so many years with a disease, and you don't just live, you get some treatment. Treatment that has some chemical stuff going into your body and all those substances are in your body. The moment you decide to have a baby, the effect of the medication may be felt by the baby. That's how I think about it." (F, 30, HS, serodiscordant couple)

> "The boys are healthy. All three of them. *You had them via caesarean section*? Yes. I delivered them by caesarean section, I didn't breastfeed, they were planned pregnancies so to speak. I was careful that my viremia was undetectable, my CD4 was good, everything was fine. I changed the treatment depending on what was going on the pregnancy, I was paying attention to all these things." (F, 32, HS, serodiscordant couple)

In comparison, men living with HIV seem to have difficulties with obtaining custody of their children, which are related to gender and the Romanian legal/cultural system, rather than the HIV diagnosis per se.

> "*Do you have a little girl?* Yeah, she's eight. *Is she staying with you? Is the little girl okay?* She's fine, she's healthy. She' s got nothing, nothing. She doesn't even live with her mother's anymore either because we've been to court. She lost her parental rights. And then the court said she couldn't stay with me or my brother either, because you are two men and it is considered that 'God forbid, you may abuse her'. And I said, I'm not giving her up for foster home, I will turn her over to the woman who raised me, here she is. And I'm leaving the girl with her for good. Permanent placement [*with a Catholic NGO*]." (M, 32, HS, no serious relationship)

Finally, serodiscordant couples seem to have the same family planning difficulties as other couples, where the decision to have children is based both on one partner's HIV diagnosis and the extent to which both partners are ready for this major life change.

> "Would you be prepared to take a risk? Yes, if we agree to have a baby, yes. After all, I know there is. Yes, you are taking a risk. The chances are minimal, not that great. I mean, I know the odds aren't great, and if it happens, it could very well happen to me, or it could happen to someone else. At least it's a conscious choice. I'd like to think so, conscious. And it's my choice, I go for it in the end. [...] Theoretically we want children. But, we've talked a lot both jokingly and a bit more seriously about this subject but at the moment I can't say that we have to let things evolve a bit more before an issue like this because it's quite a big responsibility. There is great responsibility for this step. It's a big responsibility without even thinking about it, but it's doubly so and we have to let things evolve a bit. We can't decide like that, at least I can't. Rather than an accidental pregnancy, which is not a decision. I wouldn't do that easily. We're in no hurry. Basically, I believe that to create a new life, health must be at its best. You have a responsibility in that sense. If your health is not at its best, there is no justification for doing anything outside that would put you under greater physical and all-round stress. It's like when I'm not as good as I can be at my job and I go on hiring other acolytes, other apprentices. I can't. I need to be at that teaching stage." (M, 30, HS, HIV- partner in a serodiscordant couple, together for 9 months)

2.3 Sexual relations and safe sex practices

2.
Interpersonal level

HIV DIAGNOSIS AND SEXUAL RELATIONS
Sexual relations and safe sex practices

I would now like to discuss on your partners and the prevention methods you use... Your sexual partner: type of relationship - steady/casual. HIV transmission prevention methods – preference and use. Last sexual contacts and prevention method used. Familiarity with protective practices: Post-exposure prophylaxis; antiviral treatment (AVR) as a prevention method (undetectable viremia); pre-exposure prophylaxis (PrEP)?

Of the sample, 11 HIV-infected people were not, at the time of the research, living with a partner or in a steady relationship. These individuals are men, either heterosexual or MSM, who use any of the three HIV disclosure/concealment behaviors (cautious, categorical, strategic).

In terms of casual sex, 7 out of 11 HIV+ men have had casual sex in the past year – 2 out of 4 in the heterosexual male group, 5 out of 7 in the MSM male group. Due to the structure of the sample no further socio-demographic inferences or comparisons can be made regarding predispositions for casual sex. However, depending on the gender and sexual orientation of the HIV-infected person, differences in attitude can be observed:

HIV-infected women prefer sex with steady partners. Incidentally, when I talk about past relationships, it is predominantly about a stable couple partner or abstinence. HIV-infected women appear to be responsible, aware of the risks involved in sex, cautious and predominantly uninterested in casual sex.

HIV-infected MSM prefer sexual relationships with steady partners, but mention the context of Romanian society and accept the limitations of the MSM relationship. In other words, they tend to be open to casual relationships, but predominantly hope to find a steady partner. Moreover, HIV-infected MSM appear to be responsible, aware of the risks involved in sexual relationships and very cautious in selecting partners (whether casual or steady).

> There was only oral sex involved. Since I broke up with ***, I haven't had anal sex at all, neither active nor passive. Because I, on top of the fact that I need chemistry to have complete sex, not just strip down and get dressed and leave. I'm very, very afraid of catching something else. The condom can break, no offense, but it can break. There are those micro frictions that if it hasn't lubricated enough, it can micro crack and I might get something. And I don't have the guts. I have said that until I got into a relationship where I... My ideal relationship would be to have someone else in the problem with me, because then I could control his treatment and see him when he takes it, so I could be one hundred percent sure. I could also be with someone who takes PrEP. Because I know he wouldn't give me anything." (M, 34, MSM)

Heterosexual men infected with HIV prefer both steady and casual sex. Those who are already in a couple or are HIV- partners in a serodiscordant couple tend to be responsible, aware of the risks involved in sexual relationships and specific in partner selection. In contrast, HIV-infected heterosexual men who are not in a steady relationship appear to exhibit high-risk behavior involving the potential contamination of sexual partners to whom they feel no obligation or responsibility. The justification for hiding the diagnosis involves a dishonest attitude in order to obtain casual sex.

"Did you have any discussions before starting the sexual part of the relationship? It was difficult to start a sexual relationship that was part affection, but at the same time it was partly reluctant. It can be very difficult to make that decision. But in the end, we weighed the situation well, we got over it. *Is she now detectable or undetectable?* She's undetectable." (M, 30, HS, HIV- in serodiscordant couple)

"You currently have no girlfriend? Are you looking for one? No. I still flit from flower to flower like this, but well, protected. With the girl either, let's say. If I don't meet her that night and I don't know what, that happens to us in that club, but I don't tell her. I tell her that we had better protect ourselves, because I don't know what you have, you don't know what I have, period. If you want it so fine, if not, goodbye. *What if it were a serious kind of relationship?* Yes, yes, yes. I would tell her." (M, 32, HS)

"I'd rather just do it protected and well-protected, take a high-quality condom and not tell her I have HIV, because she won't have sex if...especially here...here it's really sensitive stuff." (M, 42, HS)

All of the people (21) interviewed in this study cite condoms as the most commonly used, most preferred and most effective method of preventing HIV transmission.

"Anyway, we have always protected ourselves. He loved me so much that even though he didn't know if I was undetectable or not, I used a condom. So, even with condoms you don't get any of those viruses." (F, 31, HS in serodiscordant couple)

Sexual instances in which HIV-infected people have not used means of prevention are specific to couples with similar diagnoses (on treatment or undetectable) and unplanned situations.

"- *What about sex, protected/unprotected, how do you approach it or have you ever discussed it?* Yes, at first, we protected ourselves and then we no longer did it. That's it." (F, 36, HS in HIV-positive couple)

"And before it was the same method. I mean I don't mind condoms and never have. It's just because I was drunk then... it was enough and it happened. *You know the idea of undetectable equals non-transmissible?* Yes, exactly. That's how my two partners found out, the ones who know. I told them, there you go - like that, but it's okay if you're undetectable. They were informed on this stuff too; the girls were ok while the other one... Let's say, just for the sake of argument. There was no communication. I need it, okay. She needs it, okay. Something like that, that's how it's done." (M, 44, HS)

Most are familiar with AVR treatment and low viremia as undetectable/non-transmissible. They are also familiar with post-exposure prophylaxis or know people who have used this method, but none of the people in the sample had direct experience of partners using it. In terms of familiarity with the protective Pre-Exposure Prophylaxis (PrEP) practice, 6 out of 21 people did not know what it was. Only (F, 32, HS) used PrEP, as part of the state treatment provided for HIV-positive mothers and for the protection of the baby immediately after birth. Perceptions of those who are familiar with PrEP focus on the very high monthly costs of the products (from 1000 Euros upwards) and difficult access to quality products (predominantly buying generic alternatives online based on affordability).

2.4 Discrimination and stigmatization

2.
Interpersonal level

LIVING WITH HIV IN ROMANIA
The behavior of people around

Have people around you changed their behavior when they learned of your diagnosis?Discrimination – friends means community.
Stigmatization – social isolation and professional (un)fulfilment

This section concludes the effects of diagnosis at the interpersonal level by discussing the processes of discrimination and stigmatization characteristic of HIV+ people in Romania. As previously reported, the sample includes 19 HIV-infected individuals who choose to disclose their diagnosis, 16 of whom alternatively use the hiding behavior. Section 2.1 discusses in detail the methods of rationalizing disclosure behavior as well as the motivations for hiding the diagnosis.

With the exception of people diagnosed with HIV as children, after diagnosis, most people first confess to friends, then family, colleagues and so on. In terms of addressees, of the four types identified[30] only friends (as representatives of reference communities) and workplace managers/colleagues are discussed in relation to discrimination or stigmatization processes. For this study, the following definitions were used:

- Discrimination means the direct experience of the HIV+ person in which they are treated unfavorably by another person(s).
- Stigmatization is the direct experience of the HIV+ person in which they are either perceived unfavorably by other person(s) - social stigmatization based on the diagnosis type disability certificate – and/or perceive themselves unfavorably – self-stigmatization.

Taking into account the situations in which HIV+ people chose to hide their diagnosis, there are three main contexts in which discrimination/stigma experiences were measured, namely - the medical system in Romania, social life (9 out of 19 people discuss unfavorable experiences in relation to friends, group of friends or MSM community) and workplace (8 out of 19 people discuss unfavorable experiences in relation to job retention, integration and acceptance in the workplace). The unfavorable experiences in the healthcare system of people living with HIV are discussed in detail in section 4.2.

> "Friends, they know. Some of them family not because they're old enough, parents. My sister and I don't have that much contact and it's pointless. But it's okay. No, I've changed my lifestyle a bit. Well, I'm not wearing shorts till that thing goes away. At work I didn't say because there's... until I worked in the state system, there was such a backlash. Now they've changed, that disability certificate you file for tax purposes. But I haven't had the guts to put it to work anymore because everyone's looking at you exactly... I don't know, weird like that... I mean you see weird reactions." (M, 44, HS)

[30] The four target addressees identified in this study are: friends, family (including partners), managers/bosses/colleagues at work and support groups.

As can be seen below, most HIV+ people feel discriminated against.

Table 3. Discrimination and stigmatization for HIV+ diagnosed people

No.	Participant	Typology Behavior Disclosure/Hiding	Discrimination	STIGMA
1	(F, 30, HS, HIV+/- couple)	Strategic	YES	NO
2	(M, 32, HS)	Categorical	YES	NO
3	(M, 44, HS)	Cautious	YES	YES - disability
4	(F, 32, HS, HIV+/- couple)	Strategic	NO	NO
5	(F, 31, HS, HIV+ couple)	Cautious	YES	YES - disability
6	(M, 28, MSM)	Cautious	YES	YES - disability
7	(M, 42, MSM)	Strategic	NO	NO
8	(F, 31, HS, HIV+/- couple)	Strategic	YES	NO
9	(M, 34, MSM, HIV+ couple)	Cautious	YES	YES - disability
10	(M, 34, HS, HIV+ couple)	Cautious	NO	YES - disability
11	(M, 37, MSM)	Cautious	YES	YES - auto
12	(M, 34, MSM)	Strategic	YES	YES - auto
13	(M, 21, MSM)	Categorical	YES	NO
14	(M, 32, HS)	Strategic	NO	YES - auto
15	(M, 56, MSM, HIV+ couple)	Categorical	NO	NO
16	(M, 23, MSM)	Cautious	YES	YES - auto
17	(M, 27, MSM)	Strategic	NO	NO
18	(F, 36, HS, HIV+ couple)	Strategic	YES	YES - disability
19	(M, 42, HS)	Cautious	YES	YES - disability

NOTE: * the disclosure/hiding typology identifies three types of behavior - (i) strategic ('Yes, I disclosed and yes, I hid the diagnosis'); (ii) cautious ('I did not disclose and yes, I hid the diagnosis'); and (iii) categorical ('Yes, I disclosed and yes, I did not hide the diagnosis').

In terms of context, 8 out of 13 mention unfavorable situations at work. Almost all people who choose to hide their diagnosis at work feel they are discriminated against.

> "As you can see, I have tattoos and I got a tattoo here on my back, here on my neck I have the Rainbow flag in a triangle. Because it's located in an area that's not easily accessible to me, I had to clean it somehow... and I was at work, and I asked a colleague who knew about me, using gloves, to clean it for me. And she said she wouldn't do that. That she had no problem with me, but she didn't want to do this. So gloves, on a cotton wool containing a solution like medicinal alcohol, she wouldn't do it. And you know what? The virus won't last not even for a millisecond in the air. It dies instantly. So..." (M, 34, MSM)

By comparison, about half of people who choose to hide their diagnosis in their social life (from friends or acquaintances) feel they are discriminated against.

> "In situations where I went with other friends who didn't know about me. Yes, I would hide it. I wasn't taking my pills. I was just not taking them from home at all. Even if I stayed a week or two, I didn't take them. *But why?* Because I didn't want them to know. *Would you have felt...?* Because there are some who simply take the box, go online, see it and figure it out. And then I didn't take them at all. *Why, I mean I understand you told your other friends, you didn't have any problems?* To those close to you. There aren't many. *What if you were to meet someone, get to know someone?* I wouldn't tell them, no." (M, 32, HS)

So, the workplace is both the place where most HIV+ people encounter unfavorable situations because of their diagnosis, but also the place where they might develop self-confidence.

> *"I want you to tell me about the diagnostic disclosure. Who knows about your diagnosis?* Parents, family, all the organizations where I've worked, friends, the whole community that sees my profile on dating sites and apps. *So you're very open about your diagnosis?* Yes, from the first moment I was diagnosed and saw that I had become undetectable, I put myself on this status, went to groups, admitted it. Now that everyone has access to information, it's easier." (M, 27, MSM)

The majority of women (3 out of 5), men (9 out of 14) and people living with a partner (5 out of 8) feel they are predominantly discriminated against at work.

> "I think one colleague, but I'm not sure... It's just an impression of mine. Although I haven't spoken to her for years, a colleague from my first college might have felt a little distant, but again, maybe it's just an impression of mine, especially since we haven't spoken for many years. I had an incident at work, too. But even though I have a colleague who... although she said she's ok with this stuff, there are some issues that lead me to believe that she's not. But otherwise, no. Most people I've told, and I admit I don't really care anymore. I don't really care anymore." (F, 30, HS)

For men there seem to be differentiations according to sexual orientation – where compared to heterosexual men (4) who consider themselves equally discriminated against in the workplace and social life, MSM particularly mention discrimination in social life. More specifically, it is about discrimination and concealment of the HIV+ diagnosis in the context of the Romanian MSM community.

> "I've also had so-called friends who don't know practically ... Initially, I was disappointed, but later I saw it as a selection method. Like sifting wheat from chaff, right? Hearing this stuff or seeing me in the halls of Balș, of course they made sure to get the word out to the community. And about some people it was easy for me to... *Did it affect you in any way that they spread the word?* Yes, it affects you in the long run so to speak because although the straight world... Because it's not a community, it's a world... basically they grow and change and they're much more tolerant, much more ok, much more understanding or at least they're open to listen to you, to inform themselves when they hear this stuff. Not ours. Discrimination within the gay community is internalized discrimination, very, very pervasive. I mean it's felt on all levels and we HIV positives are pariahs so to speak. Community pariah." (M, 37, MSM)

> "Outside of Romania, the gay community is not prettier, more embellished, it's the same, there are lees to every wine. But it is more educated. In Romania, the gay community is not educated. We currently have three types of gay people: guys who are either 'coming out', or who know their sexuality and don't necessarily have to admit it to others, and who are educated in context, use apps, have been abroad, etc. ; there are gay people who have acknowledged their sexuality, not necessarily to everyone, but they are not educated and they are the kind of people who hurt others and there are those gay people who don't acknowledge their sexuality, who are usually married, in a couple or have been single since the dawn of time and who meet in extremely bad places to have sex. My problem is that the first category is extremely prevalent abroad. The second category is also outside our third category. I have not seen the third category abroad. Because there everyone goes online and is informed. We don't have them. A guy in his 40s wrote me on one of the apps and said if you want to chat on 'messenger', I say yahoo messenger, yeah...well don't mind me, but I haven't used it in ten years I didn't even know it still existed. That I have a bunch on my list. It is super wrong at so many levels, do you understand what I'm saying? And I'm 34, he's 40 something ... I mean, it's not too big an age difference to say we're from different worlds." (M, 34, MSM)

In terms of behavioral typology disclosure/concealment of diagnosis and discrimination:

- CATEGORICAL people, although they have experienced episodes of discrimination throughout their lives, prefer to consider them as transient events with little impact on their lives. They seem to have little hesitation when it comes to dealing with discrimination incidents.
- STRATEGIC (8) people consider themselves equally to be and not to be discriminated against. Of those who believe they are discriminated against, they divide equally between social and workplace life.
- CAUTIOUS people consider that they are discriminated against (7 out of 8), especially in social situations.

In terms of being stigmatized, 11 out of 19 HIV+ people have had experiences where they were perceived unfavorably, predominantly based on the legally disabling nature of their HIV/AIDS diagnosis.

> *"Do you feel affected by the diagnosis?* Not now. I used to. Including at work because I worked in the food industry. *And there you had to take tests?* No, I worked for a while. I took a cooking course, I did practice at ***and where I worked, I made sandwiches, I made salads. *And you had to tell them, did they do tests or what?* I didn't tell them. Instead, word finally got out because I helped an HIV-positive girl get a job, I wanted to help her, and she blurted out. And they fired me. Not for that reason, they looked for other reasons because they didn't have the right to fire me for that reason, but they made sure they fired me." (F, 32, HS)

As shown in Table 3, the 8 HIV+ people who do not discuss stigmatization are predominantly women and MSM, especially women infected with HIV as children. In the sample, 3 out of 5 women do not consider themselves to be stigmatized because of their diagnosis/disease.

Half of HIV+ people living in couples feel stigmatized because of their disability diagnosis. HIV+ men (9 out of 14 people) mention experiences of stigma, mostly based on disability diagnosis (5 cases). Specifically, almost all heterosexual men specify this reason, while MSM predominantly consider self-stigmatization (3 out of 5).

> "- *Why hides this diagnosis*? *What would be your main argument for hiding it?* Yeah, not that it's discrimination, but you're looked at differently. You're no longer one of them, you're already infected and people are talking. I mean, you'd rather have dementia, you'd rather have leukemia and everything be OK, but don't say you have AIDS because there's a lot of discrimination in ***." (B, 42, HS)

In terms of behavioral typology disclosure/concealment of diagnosis and stigmatization:

- CATEGORICAL people do not consider themselves to be stigmatized, regardless of when they are diagnosed. In other words, they are the most resilient to situations where they are perceived unfavorably.
- Predominantly STRATEGIC people do not consider themselves to be stigmatized. The 3 out of 8 people who feel otherwise predominantly feel self-stigmatization.
- CAUTIOUS people fully consider themselves to be stigmatized, with a prevalence of disability stigmatization (5 out of 8 cases).

Overall, 9 out of 19 HIV+ people perceive to be discriminated against and stigmatized, especially MSM men, especially users of cautious disclosure/hiding behavior and who consider this to happen mostly in the context of the workplace. Furthermore, 4 out of 19 HIV+ people do not consider themselves to be

discriminated and stigmatized, and these are predominantly MSM, especially users of disclosure/strategic hiding behavior, and aged over 32.

3. The community

3.1 Community perception of the disease

3.
Community level

LIVING WITH HIV IN ROMANIA
Community perception of the disease

What is your community's perception of HIV? Has this perception changed? If so, how?

The community perception of HIV differs depending on the type of community to which interviewees referred. Thus, some of the interviewees referred to the rural communities where they grew up, a few referred to the MSM community, and most had in mind the more general context of Bucharest. Rural communities were brought to discussion by people infected as children, highlighting the efforts they had made over the years to keep the truth from coming out, because disclosure would have affected their parents and the whole family. Although it has been a long time since they left home (for Bucharest), rural communities seem to have remained just as uninformed and discriminatory towards people living with HIV, and their parents continue to be careful not to let the truth be known.

> "It's more emotional because of my parents. I am no longer affected from that perspective in any way and I see them being affected even after all this time. OK. Coming back to what you asked me...if I went now to the community where I come from, I come from a village and they would find out...I told you earlier I don't care anymore [...] Instead everything would rain down onto my parents and they would be the ones who might suffer." (F, 30, HS)

> "Look, because of the diagnosis, I had to change my residence because I don't live in Ploiești, I live somewhere around Ploiești, in a village, in the countryside...and given the life in the countryside everybody knows everybody, I had to change my home in order to be able to get all my...allowances...and I have an official residence very far away with someone else precisely because of the discrimination... Especially since I had relatives working at the town hall where I had to go with the papers and everything... After that, I would have been afraid if they found out...I had contact with their children...to create a panic for them too...because I'm sure they are just as uninformed as I was before. As forewarned is forearmed, I preferred not to alarm people for nothing, plus the fear of being pointed out by all the village." (F, 31, HS)

With regard to the MSM community, the few opinions expressed belong to HIV+ MSM people and highlight the existence of attitudes of rejection towards people living with HIV.

> "Those around me have a very, very anaphoric...convoluted reaction. I was lucky that the friends I had before (HIV) plus stayed after the plus. I don't feel like the friendship with them got any cooler or crappier, but they stayed there. And that I'm glad some chose to leave because somehow the sieve sifted and didn't impact me so much. But I have to admit that in order to survive in a gay community in Romania is for nobody to know anything. And the gay community with plus is even more fucked up." (M, 34, MSM)

Regarding perceptions of HIV among the general population in Bucharest, there is a consensus that although there are still some discriminatory attitudes, the population is better informed than in the early 2000s and the level of tolerance and acceptance is continuously improving.

> "If we were to talk at a larger level, in Bucharest for example, we would say that things are better in Bucharest. Let's say they're better compared to 10 years ago, they're better now. But still, believe me, we are a people of stigmatizes. And we don't care if the other is right or wrong. Whether or not we have violated a right. And I never think if I were them ... Unfortunately, this is how I see Romania." (F, 30, HS)

> "Somehow yes, people's perception has changed. I mean they're much more open to what HIV is...they're much more informed...only it's really not quite as it should be. But compared to the 2000s it's a far, far, far improvement on how things were 20 years ago. Yes, it has changed." (M, 32, HS)

> "Yes, it's changed quite a bit because the generations are changing too and I think young people are starting to be more informed about these things." (M, 44, HS)

> "Man, I don't think it is the same. Because now most people know that HIV is just a chronic disease and you can live your whole life as long as you take your medication...it's not the same mentality as it was back then (in 2012 when she was diagnosed)." (F, 36, HS)

3.2 Access to support groups

3.
Community level

LIVING WITH HIV IN ROMANIA
Access to support groups
Do you have a support person or group you can turn to?

At the time of the survey, 5 people in the sample were participating in a support group organized by an NGO and were very satisfied with the information and support they received in these groups: "Yes and we are also on WhatsApp, we text each other every day. It's super cool." (F, 31, HS). However, there are also people living with HIV (2 in the sample) who tried to participate in support groups but did not fit in for various reasons, as the quotes below show.

> "I participated but I don't know, I didn't really fit in, let me tell you why... these support groups have to be created with a certain category of people, that's how I see it. OK, I have nothing against those who have no education or do drugs or practice commercial sex and so on. But you can't put a normal person who has a family...well I don't have children...I'll give you an example...who has a family at home, has a stable job, has a responsibility, is aware of things, with someone who only thinks about drugs and has ended up there just because they are given a voucher. You can't create a support group like that. My opinion ... and then barriers occur. I didn't fit in." (M, 32, HS)

> "As a support group, what interested me was that the caregivers were not being considered. And I got there exactly through this famous doctor who from what I understand also admitted, but not to me, that she didn't like gay people...if she was near me...maybe I'd get away with something nasty...you have no right to say that. And then I spoke to XXX who understood what I wanted and invited me to join a group. And I went there, I liked it, it really was OK, until the tarot games... I understand, how shall I say, you have a slip, you use a trivial ugly expression, after all they are men and you can't help it. I couldn't get used to their behavior, I don't know, maybe I was born in a different time, in a different era..." (M, 56, MSM)

But all interviewees said they have people they can rely on day and night, namely their partner, close friends, psychotherapist or counsellor.

4. The medical system

4.1 Interaction with the healthcare system in Romania

4.
Institutional level

THE HEALTHCARE SYSTEM & RESPONSE TO THE DISEASE SITUATION

Interaction with the healthcare system in Romania

How would you describe your interaction with the Romanian medical system, from a disease perspective (tests, treatments, hospital visits, etc.)?

With regard to interaction with the healthcare system, HIV+ people in the study responded by reporting (spontaneously) on three main topics. The first and most frequently mentioned topic concerned interactions with doctors of all specialties and with the hospital (in general). The second issue concerns interactions with medical staff in the wards where patients pick up their medicines. Finally, the third topic reported experiences of discrimination in interactions with the healthcare system, which is dealt with in section 4.2 below.

(1) Interactions with the doctors and the hospital

All 19 HIV+ people in the sample bring up interactions with doctors. As we have already shown in the previous sections, a good (trusting) relationship, especially with the attending physician, positively influences adherence to treatment. In this respect, the sample is divided into two roughly equal groups. The first group is very critical and focuses on negative experiences. The second group is rather sympathetic and chooses to talk about positive experiences with "wonderful" or "extraordinary" doctors. Only a small number of interviewees (4) try to be balanced and report both negative and positive experiences, but still explicitly place themselves in the first or second group.

Positive experiences in interactions with doctors	Negative experiences in interactions with doctors
"Well, I have had good experiences with the Romanian medical system. I know people who don't have very good experiences. My doctor is pretty all right, although she got my regimen wrong, she is an understanding person I can talk to. The big problem is that doctors are on the run and don't give you enough time and attention. But it's not really their fault. Mostly, though, the doctors are a bit expedient ... I repeat it: there are a lot of doctors who are expedient and don't care, don't answer the phone or text or don't even pay attention to the patient. But in my	"At age 4 I was diagnosed. In Colentina, there was no Matei Balș, it was Colentina, ... and when I was diagnosed ...now I don't hold it against her, but Doctor XXX came into the room and said, in front of me, she has AIDS and he's going to die. As little as I was, I vividly remember that moment as a shock. And at that point I grabbed my mother by the legs and told her I didn't want to die." (F, 32, HS) "With me, the attending physician in the county is the one in Prahova. Who I don't really have a relationship with. As I live here, I don't really have a

Positive experiences in interactions with doctors	Negative experiences in interactions with doctors
experience, I don't have much to complain about." (M, 42, MSM) "Let me be semi-direct. Doctors don't have time because the number of patients is too high and I understand them." (M, 34, MSM) "At the time I was diagnosed, I had my family doctor somewhere in the countryside, in Teleorman County because that's where I'm from and I told the doctor [...] Although she is an old woman, but she is very friendly. Now, given that she had known me since I was a child and that she was medically trained...and I told her. She said it was ok, she made fun of me, she also gave me some strange prognosis ... jokingly, she told me about the problems, complications that I might encounter. She suggested I try something herbal as an adjuvant and it was very OK. I was worrying because, well, you know how it is, in the country, it's in the country, and I was thinking, doctor, don't tell anyone, don't spill the beans ... Iulia, the nurse ... Oh, my God, if the word is out, she is instantly fired. I mean this thing...I'm not risking my freedom for some gossipy bullshit like this and I guess she's not that stupid either. Yes, so it was very okay. In Bucharest when I moved here to a family doctor recommended by a friend, it was really OK, I had no problems." (M, 37, MSM) " My family doctor, I told him from the beginning. He's been my doctor since I was a kid. He's a very old guy, very awkward, but he had a surprisingly nice reaction, surprisingly OK. He was still a doctor, as if I had told him any other diagnosis and that was it." (M, 34, MSM)	direct relationship with her, but rather my mother who goes to get my treatment from there. [...] And she never brought up...let's do some tests where they see if I've developed any resistance...OK, it works, as the tests show it, but there are some consequences, some effects." (F, 30, HS) " In terms of communication on a scale of 1 to 10, I would say -5. Overall, I think a 3, 4. That cuts down a lot. Because I never get to see the doctor to talk to her because she is always busy. Already, if I ask the second question, I feel like I'm upsetting her or something...and I have to leave. I am ashamed to ask a third question. I mean, it's a topic you can't talk about like that in 30 seconds, but you don't have time." (M, 34, HS, IDU) "Doctors don't really do their best to tell you about the disease or inform you, talk to you, tell you what treatment you could take adjuvantly...pills to help you, boost your immunity or something. You have to inform yourself among friends or acquaintances or possibly on the Internet." (M, 23, MSM) Most negative experiences are reported by people living with HIV in interactions with dentists (7 people). Most of these experiences touch on the issue of stigmatization and discrimination and are presented in the next section (4.2).

And with regard to interactions with the hospital, ratings vary from interviewee to interviewee and from hospital to hospital. For the same hospital, two HIV+ people can give opposite assessments. However, also with regard to the interaction with the hospital the sample divides into two roughly equal groups, but with opposite dominant opinions.

Positive opinions in interactions with the hospital	Negative opinions in interactions with the hospital
"Tell me how you would describe your interaction with the medical environment here? What was your relatively recent experience with hospital admission like? I'm at Balș, in the children's ward. That's where I'm admitting myself. I trust them. Very well. To be	"That to me...what's going on with adults and the system that's thought up at Balș, it sucks. I'm telling you this very bluntly. [...] I've changed ..., I think it's the third doctor I've changed. The first one was the one that was on the children's ward, because all of my

Positive opinions in interactions with the hospital	Negative opinions in interactions with the hospital
honest, I like it. When I admit myself, after a week I come out as if I were new, so to speak. Honestly. This stuff...gets an A from me." (M, 32, HS) "At Matei Balș, I give them a rating of one thousand. For the rest of them, it's horrible". (F, 32, HS) "Hospital visits are not a problem, neither in Ploiesti nor at Balș. There were only some problems with the treatment." (F, 31, HS) "Hospital visits are not a problem. There are times when there are queues, but I already discuss it with the attending doctor via SMS so as not to disturb...when, day and time and then there is a kind of balance on both sides. The only time it gets really crowded is when medication is dispensed at the beginning of the year and towards the end of the year...in September. I never go during this period." (M, 34, MSM) "As for the staff, when I go for my treatments (to Bucharest, Balș), they are nice to me. Okay, and I smile and thank them and say hello. And it's a reciprocal thing. They behave with you the same way you behave with them. I haven't had any problems, fortunately, not being able to find my medication and having to change my regimen, especially during those times of crisis. In my experience, I don't have much to complain about." (M, 42, MSM) "Instead I was admitted to neurology in May last year, they did a lumbar puncture to see what the phase was, MRIs of my head, my whole spine and I had nothing. They were super nice. Everyone, yes." (F, 31, HS) "Babes is a crowded hospital. The ward is overcrowded. The people there are as nice as they can be, for Romania. I understand that and I don't mind. I mean, they're nicer than most." (M, 34, MSM) "I don't think I had any problems. On the contrary, sometimes I have been privileged." (M, 21, MSM) "On the other hand, I went into an alcoholic coma a year and a half ago and ended up in Floreasca. I had the pills in my pocket, [...] and they asked me what the pills were. I told them I was HIV positive on treatment and they treated me like any other patient.	generation, since 1989, were somehow divided in the children's ward and were left there because we were brought up so to speak...by the people there. And there are doctors who have known us since we were children. It's just that the doctor I had at the time decided that I was no longer on the children's ward and transferred me to adults. Then everything changed for me. I haven't had positive experiences because no one has taken an interest in understanding...let's see how you are, you're okay you're not okay let's do it, especially when you're being transferred from a ward. And you need to start from scratch. If I said things...for example...I don't know...I have joint pain or I have fat accumulation, most of the time, doctors think that these things we say...is that we're always looking for reasons not to be well. And there have been repeated demands from me...I would need to see what was going on and they have been ignored." (F, 30, HS) "Yes, I am unhappy with the ward in Arad that distributes medicines. It' s horror. And we argue a lot. They don't like the fact that I want to come to Bucharest to get the tests if they diagnosed me here. They say you are required to go to Timisoara, that there would be some sort of regional center that does CD4 and viremia. But there's a very obnoxious doctor there. She offends you, she takes you out...there was this girl, we got in line together, and the doctor said: go outside, because you don't come to me smelling like that...and she really had a nice perfume smell." (M, 28, MSM) "And I feel like the nurses there are doing me a favor by giving me the pills or something. And with the tests, with the viremia, the fact that I didn't know and it was normal to know what my viremia was, to see if the treatment works, because it might not work and I find out only after 4 months that it doesn't work..." (M, 34, HS, IDU) "And the most arrogant doctors I have ever seen in my life are those at Colentina. Especially in surgery. Very arrogant and superior. They speak in superfluous when they look at you like you're an outcast due to your disease, especially when you say you come from Matei Balș. I went there because I have a cyst [...] And when I said what I suffered from, of course they went to hum and haw. No, let's do another ultrasound ... basically an insulting refusal. God, then rebuild the Matei Balș hospital so as to have a surgery ward, a

Positive opinions in interactions with the hospital	Negative opinions in interactions with the hospital
So there's a flip side to it that's nice, but it's so rare." (M, 34, MSM)	psychology and dermatology ward and everything you need. Stop begging left and right... With the stroke I was also admitted there, in Matei Balș and I was taken for neurology. They behaved very nicely, but their method of working...they were empirical. It felt like the Middle Ages." (M, 56, MSM)

(2) Interactions with the wards from where drugs are picked up and the issue of diagnostic confidentiality

This topic is usually linked to the topic of difficulties of access to medicines, which is already discussed at length in section 1.2.1 topic (7). More specifically, the way in which wards where HIV/AIDS drugs are collected are compartmentalized and organized is most often described as severely affecting diagnostic confidentiality. The protection countermeasure most frequently mentioned by interviewees, especially from the MSM category, is to go to the hospital "wearing a scarf and a hat, so that people don't know me" (M, 34, MSM). Only one of the interviewees mentions having made an official complaint to the hospital director and the Ministry of Health.

> "On a monthly basis, you report to Ward 2 of the Matei Balș Institute. You go to the medical records office, where you say the name of your attending physician. And the doctor in charge of issuing the prescription. Next door there is the medication dispensing cabinet. The problem is this: that in the same corridor where we, the HIV-positive patients are, there are also patients having other tests. And here the level of confidentiality already drops to zero. I brought this to Mr Cercel's attention... I also left a complaint with the Ministry of Health. Trust me. The Internet is vast, Facebook is vast. People already know what those two offices are. I have brought to the attention of the Professor to compartmentalize the two offices or to compartmentalize the secretariat in relation to the two offices where patients wait. Because already the security level of privacy has gone to zero. [...] Plus this has been going on for over 15 years, really?! You are not in a position as a Minister to compartmentalize that sector which is a sector that can influence...including the psyche of a patient. Because if that patient is recognized, that patient can fall into a mental collapse and end his life, what are we talking about?" (M, 34, MSM)
>
> "But what's disturbing about Babes... my luck is... that you know me as Sebastian... but my name is not Sebastian. And this is 15 years old so it's not recent. I'll add my name to the ID now but what's disturbing about Babes, and it bothered me from the first moment...somehow, I'm covered, but I'm thinking others...you get there and fill out a bunch of forms. Every time you go there you have to sign an agreement that you came for tests, that you live there. A stack of about 5-6 documents. With those documents, with the ID and the card, you have to be in the system [...] the problem is that when they finish entering the information into the system, they call you. By your name. Not fucking OK. Pardon my French. Because you go there often, the nurses know you and know your name. That's the escape... The problem is that there are people like me who want to keep a low profile and then they send their mother, sister, brother, boyfriend, girlfriend." (M, 34, MSM)
>
> "Last year there was a period of about 3 months when the health cards didn't work and you had to go into hospital for tests and there was a queue. There were people who had been scheduled for 5 months, came in and couldn't get their tests and hence the nerves, people taking time off work, all sorts of frustrations. Another point: the moment they call your names, they call you by your full names. We understand that all of us who are there are for that, but there may be people there who just come and take their medication, cousins or other people, etc. *Isn't there a special area in the hospital?* - They're all there. There's the dispensary in the basement, the triage with the counter next to it, the doctor's office with a door that provides confidentiality,

there's a screen with two collection chairs and that's it. Everybody knows your name, why you came... not to mention that the staff are also talking out loud: hey, but did you take X HIV and hepatitis tests? They should respect some codes. I wish that when I go to the doctor he knows from the start that I am a person at risk and does all my tests, not wait for me to tell him. People who can't ask for it, what do they do?" (M, 27, MSM)

And because discriminatory attitudes are widespread in Romania (see also sections 2.4 and 4.2), several interviewees consider it extremely important that the healthcare system strictly adheres to the confidentiality rules, which give them the freedom to choose to whom and in what contexts they disclose information about their disease. Thus, these people feel exposed and deprived of their degrees of freedom. In addition to the risk of discrimination resulting from the way wards are compartmentalized, some interviewees also drew attention to the way HIV/AIDS wards are located and signposted.

"She recommended that I go to Balș to a doctor she knew. It took me about three days to work up the courage to go and I must admit, I was horrified all the way from the hospital, from the road until you get to the area...and it felt like we were in the Middle Ages when I saw that entrance that was so sinister...and it said loud and clear what was that...it's as if you were...so that entrance is like the icing on the cake. People need to know you have something. [...] So that gate is...people who have the courage to go through there and are at Matei Balș, I congratulate them because I couldn't. Especially for the gay community in Romania, it is...it seems to me... So, I preferred to go to Victor Babes. Because the entrance is more hidden...the entrance is in the basement...it's somehow more hidden. The disadvantage at Babes is that they offer treatment for every type of person regardless of social status and unfortunately they are very much focused on homeless people and etc.... and then every time, there are some smells there, some things." (M, 34, MSM)

4.2 Discrimination in the healthcare system

4.
Institutional level

THE HEALTHCARE SYSTEM & RESPONSE TO THE DISEASE SITUATION
Discrimination in the healthcare system

Only a few study participants stated unequivocally, "No, I did not feel discriminated against at all (in interactions with the medical system). The only people who know (that he is HIV+) are my diabetes doctor, my internist, my family doctor and I can say that I have absolutely no problem with them. They speak normally, everything is normal." (M, 56, MSM)

In contrast, more than half (13) of the HIV+ people interviewed reported multiple experiences of discrimination in the healthcare system. These people are women and men, of all ages, with all levels of education, from Bucharest or elsewhere and regardless of their sexual orientation, when and how they were infected or how long they have been on treatment.

The majority of discrimination situations reported by people living with HIV relates to interactions with dental practices (9 people). Precisely for this reason, as these people explain, they postpone dental treatments, although they have problems in this regard or even "very damaged teeth". Only with regard to the Faculty of Dentistry and the ARAS-run practice is there a consensus that they provide quality and non-discriminatory services.

"I had to go to the dentist. I once went to Alexandria and told the doctor there (about being HIV+). The reaction was negative and at the moment I was annoyed and wanted to lodge a complaint, but being there, locally, I was afraid. I'm pretty well known there and I was afraid to go and lodge a complaint. Instead I went to another doctor whom I told and he apologized on behalf of his colleague and he received me without any problem and everything was all right. In Bucharest, most of the time when I had problems, I went to the Faculty of Dentistry where they behaved impeccably." (M, 37, MSM)

"It only happened to me once when I went to the dentist. And he said he wouldn't see me because of my diagnosis... And then he called me to go to another practice and attended to me there. He didn't have anything against it, only his superiors said no way." (M, 28, MSM)

"Yes, I had a problem once, I went to have a tooth pulled. As a matter of course, the ARAS has a practice for that, that's where I used to go. But then I went to a practice closer to me and when I told them I had HIV, they sent me to the Faculty of Dentistry. But other than that, no." (M, 34, HS)

"Have you ever needed a dentist? Yes, and I've been turned down by many. In the end I found one through the Italian woman who raised me, she accepted me and I can always go there (to Italy)." (M, 32, HS)

"There was a situation last year when I got my wisdom teeth pulled. When I told the staff, I was HIV+ they froze. I asked them if they didn't know what that meant as they went to medical school. I told them I was undetectable... And the next time I had to lie, anyway I know nothing happens, I don't put them at risk because I have no concentration in my plasma, I'm undetectable." (M, 27, MSM)

People living with HIV reported situations of medical discrimination also in relation to:

- emergency services

"For example, before I gave birth, I had a motorcycle accident. I went to the emergency room...I didn't want to tell them...the person I was with kept telling me to tell them, tell them.... He bandaged me up. He didn't say no to me, but when I told him (that I had HIV) he didn't even clean me...I had some of that paint from the door." (F, 32, HS)

"I took the taxi and the taxi drove me there, my friend couldn't explain very well where to take me, and the taxi took me to the emergency at Babeș Hospital, not to my ward. The Babeș ward refused to have me, although I was almost dead. We arrived at the Babeș Hospital and, go figure, we caught the shift exchange. And nobody paid any attention to me. And they kept me in the waiting room. At 9 o'clock they picked me up and told me they didn't have any more pills to give me, that I had to go and buy them myself and they couldn't admit me because they didn't have any more places. And they sent me home. And it was before my salary, I somehow got the money, whatever, I paid about 400 for the pills. And I stayed home for a week. Nobody came, well, my friends did but ..." (M,34, MSM)

- ambulance services

"I can give you last year's example. I got the flu [...] and the flu started somewhere on Sunday night really bad, around 4 o'clock in the morning, I felt like I didn't...that we had to go to the hospital because I didn't...I felt really sick. I called the ambulance, and because it's nice to say what you have (HIV+), they wouldn't take me. So the ambulance in Romania didn't want to take me, I had the flu." (M, 34, MSM)

"We were working on the Tunari road, somewhere remotely, in the middle of the forest. I got sick at work and called the ambulance. The ambulance came, and they asked me if I was on any treatment. I told them I was HIV positive, not on treatment and they wouldn't give me anything. So they opened the door, and I was standing by the door and from the ambulance, the nurse was talking to me. My luck was that the company manager came, who knew my situation, and I had to call her by my side to explain that these people would not let me into the ambulance. So yes, I avoid anything hospital-related." (M, 34, MSM, IDU)

- dermatology wards

"Yes, I've dealt with dermatology. Well, I went over there and he said to me "come and get undressed, why are you here"...something like that. And he started accusing me of getting to the level where drug users deliberately infect themselves just to get pensions. And the best part...the moment they are infected they are also referred to us, i.e. to dermatology. And he complained that: we do nothing but encourage the spread of this disease precisely because these benefits are given. It' s absurd." (M, 32, HS)

- gynecology wards

"You've been through three deliveries, tell me a little... At Giulești, awful! I don't recommend anyone to go to Dr. XXX. In addition to not being talked to, I also gave him a truckload of money...over their nurses, nurse aids...I think I gave more money than I gave the doctor. [...] With my second son, at Cantacuzino, I came across a doctor who was a lecturer...she insulted me, she called me the worst...she asked me why I had children...she made me give my signature so they could tie my tubes so as not to have children anymore ... she insulted me...I can't say any more. [...] But with my third son, there was no problem. Dr. YYY operated on me, he's a million bucks. I mean, I'd call him at 11 P.M. if I needed anything. I'd call him on the weekends, he'd call me in for a checkup, he did everything he could...all the ultrasounds and everything...he didn't want to refer me to private clinics and pay for them. He did it all for me there for free. He didn't charge me a penny. I wanted to give it to him and he wouldn't take anything." (F, 32, HS)

- other hospital wards

"I have had many situations of discrimination. I'll give you two examples. The simplest. [...] And at one point during one of these heart check-ups, I was taken by ambulance to a hospital, I think the County Hospital in Ploiești... when the doctor heard that I had HIV, he put on his gloves. It was just an EKG, let's get this straight...he put on gloves and when he was cupping me he would ask me ironic questions like how many kids I had, somehow the fact that I'm infected is due to my sexual activity and... stuff like that. That was one, and another that was much tougher..." (F, 30, HS)

"And then in the hospital. I was hospitalized elsewhere, at the Obregia to be exact, about 7-8 years ago...and, well, you can imagine that doctors tell each other the diagnosis and even at the Obregia when they heard I had HIV, they gave me a different plate than the others..." (M, 32, HS)

- at the level of the public healthcare system as a whole

"There is a lot of discrimination against the social categories from which the sick come. And this is true on every other field. New doctors in residency are differently educated and are more grounded in everything that is social worlds. But the older ones are still jerking. If you're a drug addict and that's how you got HIV and you come to take your methadone, they look at you like trash in most cases. If you're dressed nicely, if you speak nicely, it doesn't happen, it's true." (M, 27, MSM)

"But have there been situations of discrimination? Probably if I saw some gesture that I was gay, I might raise an eyebrow, but I haven't seen anything on its face to discriminate. Instead, I have seen discrimination on the Roma side, on the side of people who take drugs...I have seen discrimination on this side. But personally, no one discriminated against me." (M, 23, MSM)

Some interviewees differentiate between experiences in private clinics and those in state hospitals. These individuals claim that interactions with staff and doctors in private clinics are fair and free of discrimination. None of the study participants reported any experience of discrimination in a private clinic (other than dental).

"Discrimination, yes, there was discrimination in the state system. I told you about that bad experience at the City Hospital, yes. Since then, in the state system I don't say anything, in any check-up at a state clinic, I hide it

(HIV+). Well, obviously not at Balș where it's not a problem. I have not really encountered any in the private (system). I usually go to the same XXX clinic because people know me there... In private I have reported it every time (that he has HIV) and there have been no problems...including my dermatologist who knows and who has remained my doctor and who really is no problem." (M, 44, HS)

"I've always said I have HIV to the doctor so I can get the right treatment...I'm talking about a private clinic. They were very fair and never mentioned it in the forms or in the reports, because I asked them not to mention it. At the last interaction with said private clinic, I stated and didn't get to tell them that I didn't want it mentioned...it happened just this month...I got sick and went to said private clinic. But with the Corona virus hysteria...Ah, well no, you have the Corona virus. Sir I don't... it was a whole story. I was trying to explain that I didn't have Corona and my problems were different. Well, they insisted. They isolated me, sent me with the ambulance to Balș, with the report of course now to the private clinic, now it can be seen that I am HIV positive. I didn't get to tell them I didn't want them to mention. I don't think they would have listened to me." (M, 42, MSM)

"The result was handed in privately and the only thing that bothered me about them (XXX Lab) is that they notified my GP. And they're not allowed. It's about privacy. Article 7 of the Constitution or whatever article that is. I read a lot, you know. But the situation between me and the GP has calmed down because he's a GP who keeps his reputation very well...he's not the kind of person who spread the word out." (M, 34, MSM)

Despite all these negative experiences, reactions from HIV+ people have been limited to "I told him a piece of my mind" or changing doctors. Only two of the 13 people in the sample who had negative experiences responded with formal referrals or complaints at hospital level or above. Other people explain that "I'm not the type" or "it's too much trouble" or talk about the fear of possible repercussions, especially as they still have to undergo all sorts of treatments. The fear is all the more acute in the case of negative experiences in smaller towns or rural areas, where there is considerable reputational risk (gossip, word of mouth).

"I was in 9th or 10th grade, I had a little cyst under my eyelid, under my eye. And I went to the doctor in Ploiești and he told me that it's a small cyst because of the dust that has accumulated and I need a small operation, very simple. When I was there, the doctor in question was only on call, she couldn't operate on me and told me to come the next day so the doctor could operate on me, that it wasn't relevant that I was infected and it wasn't serious. When we went the second time, my mother also told the other doctor that I had HIV and refused to operate on me. And my mother went and lodged a complaint with the College of Physicians, and the College of Physicians forced her to do the surgery. What was harder is that I went to the operation and on the operating table, they tied my hands and legs, they wouldn't give me anesthesia and the doctor while operating on me told me that this happened to teach your parents a lesson not to lodge complaints against doctors anymore." (F, 30, HS)

"Yeah, everybody's okay. Only at the dental office, I encountered a doctor who rejected me unjustifiably and the support group said I could report her, that it was not fair what was happening. I didn't bother, because I didn't have the mood, I'm not the type." (F, 31, HS)

4.3 Counselling and support services

4.
Institutional level

THE HEALTHCARE SYSTEM & RESPONSE TO THE DISEASE SITUATION

Counselling and support services

Did you receive counselling/support before/after testing? If so, from whom?

Neither diagnosis nor treatment is associated with any kind of counselling or psychological therapy, although this would be so necessary at least at the beginning of treatment and during periods of 'mental breakdown'.

> *"When you went for testing, did you receive any kind of counseling before or after testing?* They didn't even have the time. As usual, the Romanian medical system which is down...doctors don't, no matter which clinic you go to, don't take the time to do the pre-counselling you mentioned earlier. And this already puts the future or non-future patient at a mental disadvantage." (M, 34, MSM)

> "I was feeling very sick from the treatment. [...] I mean, yeah, no one explains or at least they didn't take an interest...well boy, let me see, I don't know either...she probably wasn't an HIV specialist, let me call, let me see...I mean none of that stuff." (M, 34, HS, IDU)

Research participants who were infected as children recall that at the time of their diagnosis, counselling services were not available, medical knowledge was not very advanced, the topic was taboo, and doctors were also tempted to associate HIV with premature death. The parents, therefore, did not understand what HIV was either "and for them, every year that passed was a relief", after initially receiving a prognosis "that if (the child) reaches the age of 18, it's fine" (F, 30, HS).

> **About the 90s:**

> "There was no counselling in 1994 (when she was diagnosed)." (F, 32, HS)

> "At that time (1999, when he was diagnosed) I think even the doctors were not so well informed and didn't know exactly about the course of the disease and so on. Because I've heard so many stories that the doctor used to say to the parents: "what are you bothering with schools and so on, he won't live much longer anyway". (M, 32, HS)

Over time, counselling and support services for people living with HIV have been developing, but very slowly. One participant illustrates cases with limited understanding of medical issues and who, at least in theory, would need counselling and sustained support to ensure adherence to treatment. This person grew up in a foster home for children, was infected as a child, but didn't learn her diagnosis until she was 23 (although she was taking medication, she didn't know what kind of medication she was taking or why she was taking it), and then had long periods of treatment interruptions that led to a worsening situation until she ended up in the hospital weighing 35 kg and with extremely low immunity (CD4 was 8). It was only after this crisis situation that she took care to take the appropriate treatment as recommended.

About 2011:

"Did you receive emotional support and counselling, i.e. did they explain all the details? They explained...they told me that it doesn't have to be a tragedy, if it was like that...OK. *Did you understand what those people told you?* Yes, I understood because I asked them nicely to speak to me more illiterately, because I didn't understand the medical terms." (B, 32, HS)

Here is how a participant in the study who is part of the priority groups targeted by the National Strategic Plan (he is an injecting drug user and took the initial test when he was detained in Jilava, in 2017) describes it: "The first test came out as suspicious, with the second one I went to Matei Balș. When my tests came back, a lady nurse came to me, and said: you have HIV, take these pills and she closed the door." (M, 34, HS, IDU). Or the description of the advice received at the initial testing in 2017 which was provided by a medical student member of the MSM community:

About 2017:

"I got slammed, I even had a little altercation with that doctor. She gave me the usual set of tests that are done when a result comes back positive. And I saw CMV there and I knew it meant cytomegalovirus, but I didn't know how to interpret the value. I asked the doctor what that CMV value was. And she told me that she was not an encyclopedia and that I could Google it, that she saw me as an open-minded and smart guy and that I had a smartphone and I had access to information and technology and I could... "you can Google it," something like that. With a very arrogant attitude and I even took the phone in front of her, took it out, wrote cytomegalovirus and told her, look what the first results are, if you read them all you have the impression that tomorrow you will die, I ask you because you are a healthcare professional... And, that was counseling." (M, 37, MSM)

An indication that counselling and support services have developed in recent years is the fact that 3 out of 6 respondents initially tested in 2018-2019 say they received counselling and support that they were satisfied with. Counselling was carried out by the attending physician or a hospital psychologist.

About 2018-2019:

"I'm one of the lucky ones because my attending physician takes his time. At least once every two months, every three months, I still talk to him. We used to meet every month. He is very communicative, very patient. Even if he doesn't have time, he tells you and then details absolutely everything he wanted to say. At the next meeting, he. elaborates on it" (M, 42, HS)

"Yes, I received counselling. After the first confirmation and after the second confirmation, my attending doctor talked to me a bit, told me a few things, encouraged me somehow. I had some questions, I asked them, he answered. But I didn't ask very much because I had known quite a lot about HIV anyway, for years...for many years I knew what HIV was and all the issues and I didn't have much to ask." (M, 42, MSM)

Others had positive experiences of accessing counselling and support in other hospitals or wards. Most (but not all) of these cases concern private clinics or hospitals.

About 2018-2019:

"First, at the clinic I got support after the test. I took the test at a private clinic. The doctor called me...look, you did some tests, you will talk to my colleague, but please go to the lab at Grivița to talk to...and there was a psychologist there, who was the head of the lab...look, we are doing another test, it's not a sure thing...there is treatment...exactly the psychological support that was expected. After that he referred me to Balș." (M, 42, HS)

"Instead I was admitted to neurology last May [...]. They were super nice. Everyone, yes. They even told me that I can get psychological counselling, that they had a good psychologist, if I wanted, I could go." (F, 31, HS)

However, counselling and psychosocial support services foreseen in the National Strategic HIV/AIDS Plan 2019-2021[31] are not yet sufficiently developed. Therefore, each person finds their own way out of the crisis situation, with the help of friends, social networks or by paying for services.

> "I had reached a saturation like that...I didn't want to take the pills anymore...I hated them somehow...then I turned to and discovered therapy and did many years of psychological therapy. [...] Yes, I pay for it, but that made me more aware of things...I don't know...after that I started to grow, to ask myself questions like: what is my life, what can I do, what am I good at in this world...and slowly-slowly when I started to realize that I have qualities and that I can be useful somehow to society or to people close to me, I started to take even more care of myself." (M, 32, HS)

NGOs are the ones mentioned as providing the only constant support for HIV information and treatment, access to drugs, equipment, psychological counselling or legal assistance. In part this may also be an effect of the way in which the study participants were recruited through collaboration with NGOs.

> **About 2013 and the present:**
>
> "When I was diagnosed in 2013, they (counselling and support services) didn't exist. I was sent to another infectious department to talk to a doctor. At the time I didn't really understand, it seemed like a lot of technical words... At the moment, having worked with ARAS and with CHECKPOINT - the first association in Romania for MSM, now there is some advice, things have evolved. At the state-owned companies, they still give you some general information, refer you to the infectious disease specialist, and if the specialist doctor is one who does his job he/she'll sit down with you and talk, otherwise you're just one of the many patients he/she has and that's it. And he/she'll probably refer you to the hospital psychologist. But in the NGO area, counselling and emotional support services have developed much more." (M, 27, MSM)
>
> "And last February, a friend of mine from ARAS helped me find a doctor in Bucharest because until then my father had been forced to go somewhere and take the pills and send them by means of a bus. And I found my doctor in Bucharest, at Balș, and he changed my treatment plan after I asked him and explained it to him." (M, 21 years old, MSM)
>
> "After going crazy, I was paralyzed. Incontinence...the incontinence came before the paralysis, the sphincter stopped, the muscles here and after that I was also paralyzed. [...] And I know I immediately posted on Facebook, does anyone have a wheelchair I can borrow? And a boy who worked for an NGO for disabled people came right away and brought it to me in a few hours...and my mother, when she saw the wheelchair said that I don't need it...and I said, "Yes, mother, I can't walk anymore, I want to go out, take me out." (F, 31, HS)
>
> "Honestly, yes, I still turn to ARAS, Sens Pozitiv and to information, even when pills were missing from the hospital she (person from an NGO) helped me with pills and so on." (M, 32, HS)

[31] Ministry of Health (2018) http://www.ms.ro/wp-content/uploads/2018/11/Anexa-la-HG-Plan-National-HIV-2019-2021.pdf

5. Social benefits

5.
Structural level

SUPPORT POLICIES
Social benefits

What social benefits do you receive? Did you have any problems in preparing the files or in the application process?

Of the total sample of people living with HIV, almost all receive a monthly HIV/AIDS food allowance (amounting to RON 16 per day), about half (9 out of 19) have a disability certificate[32] and 2 people reported that they also have a sickness pension (a third case is on sick leave and preparing their retirement file). In addition, people who have a disability certificate and live in Bucharest have also applied for the incentive for adults with disabilities granted by the Municipality of Bucharest (worth RON 500 per month).

The first problem mentioned in relation to social benefits concerns access to information. Thus, of all the participants in the study, only those diagnosed in 2018-2019 who received counseling in the healthcare system learned about the social benefits early in the process. People diagnosed in previous years have been informed or found out about these benefits from other HIV-infected people or through NGOs.

> "I remember in 2014 I went to ARAS for communication and computer courses and that's when I first came into contact with people who were HIV positive and that's when...I got a job at a social work company and they opened my eyes and I went and got one of those (disability) certificates." (F, 36, HS)

> "[In 2019] At Matei Balș, I went...to a lady nurse, I don't remember her name, but she was an extraordinary woman and spoke so beautifully...encouragingly. She also gave me information about benefits and the degree of disability." (M, 42, HS)

The preparation of the file, the submission of the file to the General Directorate of Social Assistance and Child Protection, the assessment process by the Directorate specialists, the interaction with the Committees for the assessment of adults with disabilities did not pose particular problems. Some survey participants even point out that, compared to medical professionals, the employees of the General Directorate of Social Assistance and Child Protection, while they may be jaded or indifferent, are "much less discriminatory".

> "*Did you have any problems in preparing your disability classification file?* No, I didn't have any problems. Neither at first filing nor for the reviews. There were no problems with the paperwork because I knew exactly what paperwork I needed to bring. You know exactly what you have to do, and the certificate says what you have to come to the review with, so there are no problems here." (M, 44, HS)

> "[At the General Directorate of Social Assistance and Child Protection] I'm much more OK from that viewpoint whereas the doctors in that polyclinic are a bit more awkward and the nurses too, the social workers I know are well prepared. I know how to proceed with each case and without getting into any arguments. Gossip...

[32] Persons classified as disabled range in grade from mild to severe, depending on the values recorded for viremia and immunity (CD4). Only 2 people received a permanent certificate, the others had to come up for review every one or two years. In correlation, these people receive allowances of RON 375-500/month. One of the interviewees (with severe degree) receives RON 1263/month salary for a caregiver. Disability rights include free urban transport, 12 free train journeys per year, exemption from house and land tax, car tax, exemption from income tax, etc.

after a patient leaves the doctor...the doctor and nurses gossip more than the social worker who steps back and leaves. It's all about attitude here." (M, 44, HS)

"There was nothing difficult, everything was ok. And the committee were very fair and I liked the way they asked the questions, they didn't rush you to answer, they gave you time to wait, even the small clerks didn't ask you stupid questions. There were a few others that were a little more prickly, typical of the civil servant, but on their own they recovered. All you had to do was look a little more puzzled or angry, and then they'd come to their senses." (M, 56, MSM)

However, some interviewees drew attention to the fact that General Directorates of Social Assistance and Child Protection (in Bucharest, but also in other counties) do not have the room to ensure confidentiality in the assessment process.

"I'm just asking if you've ever felt situations of discrimination, of violation of privacy? Yes, of course. Just the other day there was an event where I got really annoyed. I'm going to leave a complaint with Digi 24 and Realitatea TV because one of those inspectors (from the General Directorate of Social Assistance and Child Protection) came out and I said...but don't you have a conference room for private discussions? Because it's my privacy. He said they didn't have that. Well, what do you mean you don't have a room for that? Really?! He looked at me with a weird expression and blushed. I don't care that you blushed, answer my question." (M, 34, MSM)

"It's the food allowance which in 2016, when I was brave enough to join, was RON 13 a day, for you to eat. It is now RON 16. But to do this you have to go...because nobody knows where you have to file... and you go to four or five institutions to find a counter in the attic of a house where you can file the file and until you get to the counter in the attic of the house you go through situations so humiliating and so inhuman that you can't imagine, everyone crowded together in a big room... So, the procedures are not even transparent and... absolutely nothing. I sent my friend's mother-in-law and they made the 60-year-old woman cry." (M, 34, MSM)

There were no delays or malfunctions in the payment of benefits. However, two problematic issues were raised by the people in the sample. The first issue was highlighted by people with declared residence in another county. In their case, because benefits are not paid by card, they need their parents' help to collect the amounts from the County Agencies for Payments and Social Inspection, which requires expenses and effort not only on their part but also on the family's. The second aspect referred to the concern/fear that, in the context of the pandemic caused by COVID-19, they will not receive or will receive a reduced amount of the incentive granted by the Municipality of Bucharest (PMB). Although there was a delay, subsequent to the study, the PMB announced full payment of incentives for adults with disabilities.[33]

"At least at the moment, as an unemployed, I depend financially on my father who...because of the fact that the money I receive from the state for being HIV positive, I can't receive it on my card, I can only receive it in cash if I am in my hometown. And since I'm not there, there's been some talk that my dad could collect it and send it. And I don't have the possibility to change my address on my ID to receive them here." (M, 21, MSM)

A final point to highlight is that there are people living with HIV who give up some of their financial rights for fear of discrimination or even at work because of discrimination. Thus, according to the current regulations, in order to benefit from the tax exemption on salary income, HIV-infected people must submit with their employer a disability certificate showing the disease code. As this code "can easily be found on

[33] March 27, 2020 announcement: https://www.economica.net/primaria-municipiului-bucure-ti-revine-asupra-deciziei-de-a-suspenda-pentru-o-luna-ajutorul-pentru-persoanele-cu-handicap_181891.html

the Internet", filing the paperwork is tantamount to public disclosure of the diagnosis in the workplace, which significantly reduces the degrees of freedom these individuals have to decide when, how and, more importantly, to whom they wish to share the information. It is precisely for this reason that people who report discrimination in the workplace (and there are many of them) waive this right to reduce the risk of unwanted exposure and to preserve their degrees of freedom.

> "*What disability classification*? Ah, they placed me in the severe classification, I was in the moderate classification but my doctor said... I'm granting you the severe classification here... you see you're on the first but I've put you on a 3rd so you can get some rights. *Well, what rights does that mean*? Well, there are a thousand RON cash on a card, free public transport, 12 round trips by train, I don't have to pay the house tax and I could also get some money from the health insurance company (tax exemption), but I'm afraid the school secretary will find out if she looks at that code... and worry that I have AIDS and... They give you a code there, it doesn't write the disease, but they give you a code and if she looks online she sees immediately what the code is. *And you're afraid the secretary will find out?* Yes, she will go to the others saying, ... Oh my God, he has ... she never had something like that ... I mean ... it's that shock ... yes, there might be discrimination, so I would rather prevent that. There is discrimination in education." (M, 42, HS)

Another strategy of people discriminated against in the workplace is to go on long-term sick leave and then file for retirement due to illness.

> "From work, yes, I am still discriminated against and now I have decided to go on a sick leave that I can take and then submit my retirement file in... To wait for a year and six months of sick leave to pass and then they said it automatically activates the retirement file." (M, 28, MSM)

Even if the social benefits they receive do not amount to much, for the interviewees they represent a "useful budget", generally used for much-needed medicines in addition to those received free of charge as treatment.

Conclusions and recommendations

"Life with HIV especially in Romania is a ... battlefield. It's true that it's slightly better than in other countries such as those in Africa." (M, 27, MSM)

This research presents the individual experiences of people living with HIV in Romania. The narrative of life with HIV puts into perspective the individual, inter-personal, institutional or structural aspects that define the relationship with the disease.

The analysis revealed that life with HIV is shaped differently depending on several aspects: the age at which the person was diagnosed (diagnosed as a child and diagnosed as an adult), the extent to which the risk of infection was consciously assumed or not (people diagnosed as adults who assumed the risk - unprotected sex, injecting drug use and people who did not assume the risk - infections at the dentist/ hospital/ as a result of abuse), gender, sexual orientation or the presence or absence of a stable partner.

Individual experience of diagnosis and testing is reported as generally positive, especially by people living in Bucharest. The majority of the interviewees were tested for the diagnosis at the National Institute of Infectious Diseases Matei Balș in Bucharest. The others, from smaller towns or rural areas, who as children or as adults went through the initial testing process somewhere outside Bucharest, indicate that testing was a lengthy process that involved repeated trips to larger cities, many hospitals, many specialists and the “money envelope”.

In terms of individual behaviors, all participants in the study reported that (at the time of the interview) they were following the treatment diligently, at worst with minor lapses. However, they highlighted a number of structural problems they face. Firstly, the absence of certain drugs from treatment regimens, which leads to treatment interruptions, treatment changes or adjustments, as well as the emergence of resistance to treatment which significantly reduces its effectiveness. One of the response strategies to this problem mentioned by some respondents is the intentional discontinuation of treatment in order to achieve a "black days" stockpile. A second problem is the way treatment is provided. On the one hand, respondents feel limited by the fact that they are not offered alternatives for accessing treatment (e.g. by mail) and that medicines have to be collected in person every month, and on the other hand, almost all mention the lack of organization and procedures at the ward where they collect their medicines.

The people living with HIV we spoke to actively and regularly inform themselves about relevant news, especially about treatment, especially from the internet and the NGOs they work with. Fewer people, predominantly MSM, said that they get information from friends/pals/other HIV-positive people who were infected several years ago and know more. Only 2 interviewees stated that "I don't spend time looking for information, if something comes up, it comes up" or "the doctor tells me".

In terms of disclosure behaviors, respondents are relatively evenly split between those who choose to disclose selectively, to people very close to them, and those who openly approach disclosure, both to people in their inner circle and to acquaintances/colleagues at work or in public/online spaces such as

Facebook, forums, in social campaigns or on dating pages/apps. People who have a steady partner and those who were diagnosed in childhood tend to prefer the open option.

Most respondents report that they have engaged in behaviors to hide their diagnosis. There is no narrative that does not mention at least one of the following negative consequences associated with an HIV diagnosis: discrimination, fear, shame, isolation or depression. Disclosure/concealment behavior is used in the following social situations: friends (especially towards those who are or might be in a sexual relationship), the workplace and the medical system.

HIV+ diagnosis was identified by respondents as a factor that negatively affected their relationships. For those who were infected as children, this meant multiple experiences of rejection. For those who were in a couple at the time of diagnosis, the main consequence was the end of the relationship. People living with HIV tend to talk about previous romantic relationships as traumatic events, situations in which they were humiliated and misunderstood. As a result, HIV+ people tend to readjust their behavior to disclose/conceal their diagnosis.

For HIV-positive couples, whether heterosexual or MSM, the choice of partner seems to be conditioned by the HIV diagnosis. In other words, most prefer to choose partners who also have the virus, both to avoid difficult situations of rejection/inhibition/fear, and to avoid the guilt or responsibility of potentially infecting the partner (who is not sick).

In serodiscordant couples (3 cases in the sample), the dynamics between positive and negative partners focuses predominantly on protective measures and risk-taking. Partners (2 people in the sample) who do not have the disease tend to be informed about the HIV/AIDS condition and are aware of the implicit risks of being in a romantic relationship with an HIV+ person. Serodiscordant couples seem to face the same family planning difficulties as other couples, where the decision to have children considers the difficulties that one partner's HIV diagnosis can cause, but also the extent to which both partners are prepared for this major life change.

Information provided by respondents tends to reflect a preference of HIV-infected women for sex with steady partners. HIV+ MSM tend to be open to casual relationships, but most hope to find a steady partner. Moreover, HIV-infected MSM we talked to appear to be responsible, aware of the risks involved in sexual relationships and very cautious in selecting partners. HIV+ heterosexual men who are already in a couple or are HIV- partners in a serodiscordant couple tend to be responsible, aware of the risks involved in sexual relationships and specific in partner selection. In contrast, HIV-infected heterosexual men who are not in a steady relationship appear to exhibit high-risk behavior involving the potential contamination of sexual partners to whom they feel no obligation or responsibility. The justification for hiding the diagnosis involves a dishonest attitude in order to obtain casual sex.

Most respondents are familiar with AVR treatment and low viremia as undetectable/non-transmissible. They are also familiar with post-exposure prophylaxis or know people who have used this method, but none of the people in the sample had direct experience of partners using it. In terms of familiarity with the protective Pre-Exposure Prophylaxis (PrEP) practice, almost one third did not know what it was. Only one person used PrEP, as part of the state treatment provided for HIV-positive mothers and for the

protection of the baby immediately after birth. The general perception is that PrEP is expensive and difficult to access at high quality.

The community perception of HIV differs depending on the type of community to which interviewees referred. Rural communities were brought to discussion by people infected as children, highlighting the efforts they had made over the years to keep the truth from coming out, because disclosure would have affected their parents and the whole family. Although it has been a long time since they left home (for Bucharest), rural communities seem to have remained just as uninformed and discriminatory towards people living with HIV, and their parents continue to be careful not to let the truth be known. With regard to the MSM community, the few opinions expressed belong to HIV+ MSM people and highlight the existence of attitudes of rejection towards people living with HIV. Regarding perceptions of HIV among the general population in Bucharest, there is a consensus that although there are still some discriminatory attitudes, the population is better informed than in the early 2000s and the level of tolerance and acceptance is continuously improving.

One of the main contexts in which study participants felt discriminated/stigmatized is in the Romanian healthcare system. Only a few study participants stated unequivocally, "No, I did not feel discriminated against at all (in interactions with the medical system)." In contrast, more than half (13) of the HIV+ people interviewed reported multiple experiences of discrimination in the healthcare system, especially in the public healthcare sector. These people are women and men, of all ages, with all levels of education, from Bucharest or elsewhere and regardless of their sexual orientation, when and how they were infected or how long they have been on treatment. Most instances of discrimination were reported in interactions with dental practices. Only with regard to the Faculty of Dentistry and the ARAS-run practice is there a consensus that they provide quality and non-discriminatory services.

One aspect on which there is consensus is that neither diagnosis nor treatment is associated with any kind of counselling or psychological therapy, although this would be so necessary at least at the beginning of treatment and during periods of 'mental breakdown'. NGOs are the ones mentioned as providing the only constant support for HIV information and treatment, access to drugs, equipment, psychological counselling or legal assistance.

Almost all of the HIV+ people we spoke to receive a monthly HIV/AIDS food allowance (amounting to RON 16 per day), half (9 out of 19) have a disability certificate and 2 people reported that they also have a sickness pension (a third case is on sick leave and is preparing their retirement file). Although they had no difficulties in accessing social benefits, respondents drew attention to the fact that they are not paid by card. This makes it difficult for those with a declared residence in another county who need help, most often from their parents, to collect the amounts from the County Agencies for Payments and Social Inspection.

Moreover, given the current regulations, in order to benefit from the tax exemption on salary income, HIV-infected people must submit with their employer a disability certificate showing the disease code. As this code "can easily be found on the Internet", filing the paperwork is tantamount to public disclosure of the diagnosis in the workplace, which significantly reduces the degrees of freedom these individuals have

to decide when, how and, more importantly, to whom they wish to share the information. It is precisely for this reason that part of them waive this right to reduce the risk of unwanted exposure and to preserve their degrees of freedom.

We present below the main intervention recommendations from the perspective of people living with HIV who participated in the study:

1. Access to testing and treatment

- Ensuring adequate access to HIV/AIDS testing and ARV treatment for rural and small town populations, which entails both expense and significant stigmatization risks for a generally low-income population.

2. Changes in the healthcare system

- Ensuring the availability of all the drugs needed for seamless treatment is the first priority from the perspective of people living with HIV.
- Change in the system of distribution of medicines, without monthly visits at the hospital, but sending them by mail.
- Analysis of all cases with "old" treatment regimens and reassessment of the situation with a view to maintaining or updating them with new-generation regimens.
- Developing a nationally consolidated electronic system to monitor ARV treatment interruptions[34].
- Counselling and support for cases who have interrupted treatment, to ensure that treatment is resumed, as one interviewee explains" according to the Western European model, where the moment you are plus (HIV+), you are automatically placed on treatment, whether you want it or not. It's like an obligation." (M, 34, MSM)
- Development of counselling and support services for people living with HIV in public hospitals.
- Analyzing how the wards distributing medicines are compartmentalized and modifying them to ensure confidentiality.
- Courses for healthcare professionals on issues and ways of working with people living with HIV and support groups for doctors working with people living with HIV.

"They should still go there, including in the emergency departments or in the intensive care units or where they have a first intervention on the patient, they should still be given these instructions about HIV-infected people.

[34] A system for reporting such cases is currently available at UNOPA: https://unopa.ro/intrerupere-de-tratament-arv-in-spitalul-in-care-te-tratezi-anunta-ne/

No, their perception is totally different. Yeah, ok, I'll tell you up front..., but afterwards you can tell by the way he/she behaves...today they were about to throw me out of the patient triage with a stretcher because I didn't say that.... This is where psychological support should also be provided for doctors and healthcare professionals in general." (M, 44, HS)

3. Changes in support policies

- Automatic enrolment of diagnosed people in all existing programs or at least for categorical benefits (monthly food allowance for people with HIV or AIDS)

"What's happening: the social system in Romania is down. It's not like the German one or the one like in the US where you have your license and you know that you have everything on it, ID, address, where to get your ticket, where to get your pills...what salary you get, benefits and stuff. And then by the time this law is finally implemented, a paragraph that says clearly: HIV-positive patients should get a permanent certificate...that will happen in about 30 years, I think, when there is no more HIV." (M, 34, MSM)

- To have all social benefits available by card in all counties of the country, in accordance with current regulations.

- Change in the current rules on tax exemption on wage income so that they no longer involve the employer.

"At the level of National Tax Administration Agency, so that you are able to do everything online yourself, to file for tax exemption for example...without having to go to your employer. The bureaucratic system, this is where work needs to be done. Otherwise I think there would be no problem." (M, 44, HS)

- Legal assistance provided through the General Directorate of Social Assistance and Child Protection (or support for NGOs providing such assistance) for cases of discrimination and breach of confidentiality in the relationship with the doctor/hospital, including dental practices, and the employer.

- Developing services to assist and support people living with HIV, as well as all adults with disabilities, in getting and keeping a job.

- Providing information and education activities on HIV/AIDS prevention, transmission and protective practices in the special protection system for children, especially in residential services.

4. Knowledge about people living with HIV/AIDS

- In-depth study of behaviors and quality of life of people living with HIV/AIDS by priority groups, including treatment adherence, problems in the doctor-patient relationship, interactions with the hospital.

5. Reducing stigmatization towards people living with HIV/AIDS

- Information, education and awareness-raising campaigns on HIV/AIDS in the general population to reduce social stigmatization, especially in rural areas and small towns.

Several interviewees point to developments in the medical field that have led to dramatic increases in the survival rates of people living with HIV or AIDS. But the lessons learned from the HIV/AIDS experience can be very useful as new and emerging viruses emerge. That is why these lessons must be identified and learned so that past mistakes are not repeated.

> "I feel like this, I have a feeling it's just around the corner until this disease is cured.... As Master Cercel said: people no longer die of AIDS, they die of other diseases." (M, 56, MSM)

> "And I firmly believe that in 4-5 years, HIV will clearly no longer exist. It's a retro.... virus. I spoke to Mr Cercel, he told me that by the summer we will have the vaccine. Which will be done once every month, you stop taking the medication and then you get the vaccine every 3 months, 6 months and you become functionally cured." (M, 42, HS)

Bibliographical references

Dunkle KL, Stephenson R, Karita E, Chomba E, Kayitenkore K, Vwalika C, Greenberg L, Allen S. (2008) *New heterosexually transmitted HIV infections in married or cohabiting couples in urban Zambia and Rwanda: an analysis of survey and clinical data*. Lancet. 2008;371(9631):2183–91.

European Centre for Disease Prevention and Control/WHO Regional Office for Europe (2019) *HIV/AIDS surveillance in Europe 2019 – 2018 data*, Stockholm: ECDC, available at: https://www.ecdc.europa.eu/sites/default/files/documents/hiv-surveillance-report-2019.pdf

ECDPC - European Centre for Disease Prevention and Control (2018) *Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia: 2018 progress report.* Stockholm: ECDC, available at: http://cnlas.ro/images/doc/ecdc_continuumOfHIVCare.pdf

Eyawo O, de Walque D, Ford N, Gakii G, Lester RT, Mills EJ. (2010) *HIV status in discordant couples in sub-Saharan Africa: a systematic review and meta-analysis*. Lancet Infect Dis. 2010;10(11):770–7.

Frew, P.M., Parker, K., Vo, L. et al. (2016) *Socioecological factors influencing women's HIV risk in the United States: qualitative findings from the women's HIV SeroIncidence study (HPTN 064).* BMC Public Health 16, 803 (2016). https://doi.org/10.1186/s12889-016-3364-7

Gupta G. R., Parkhurst J.O., Ogden J.A., et al. (2008) *Structural approaches to HIV prevention*. Lancet. 2008; 372:764–775.

Kaufman, M. R., Cornish, F., Zimmerman, R. S., Johnson, B. T. (2014) *Health Behavior Change Models for HIV Prevention and AIDS Care: Practical Recommendations for a Multi-Level Approach*, JAIDS Journal of Acquired Immune Deficiency Syndromes: August 15th, 2014 - Volume 66 - Issue - p S250-S258, doi: 10.1097/QAI.0000000000000236

Kim, J., Nanfuka, M., Moore, D. et al. (2016) '*People say that we are already dead much as we can still walk': a qualitative investigation of community and couples' understanding of HIV serodiscordance in rural Uganda*. BMC Infect Dis 16, 665 (2016) doi:10.1186/s12879-016-1998-9

Ministry of Health (2018) *National Strategic Plan for HIV/AIDS Surveillance, Control and Prevention 2019-2021*, available at: http://www.ms.ro/wp-content/uploads/2018/11/Anexa-la-HG-Plan-National-HIV-2019-2021.pdf

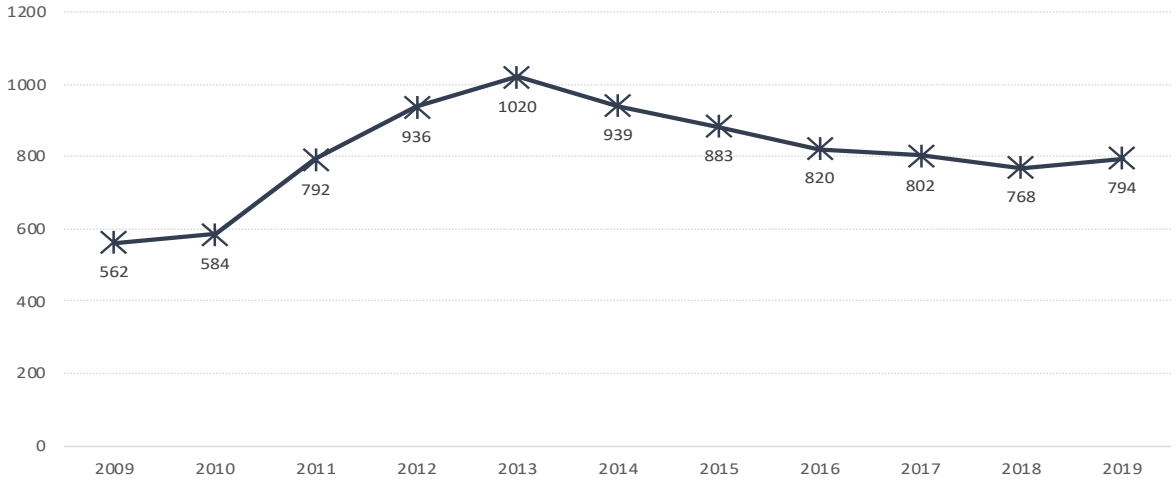
Seeley J., Watts C.H., Kippax S., et al. (2012). *Addressing the structural drivers of HIV: a luxury or necessity for programs*? J Int AIDS Soc. 2012;15(suppl 1):1–4.

UNAIDS (2014) *90-90-90 An ambitious treatment target to help end the AIDS epidemic*, Joint United Nations Programme on HIV/AIDS, available at: https://www.unaids.org/sites/default/files/media_asset/90-90-90_en.pdf

Annexes

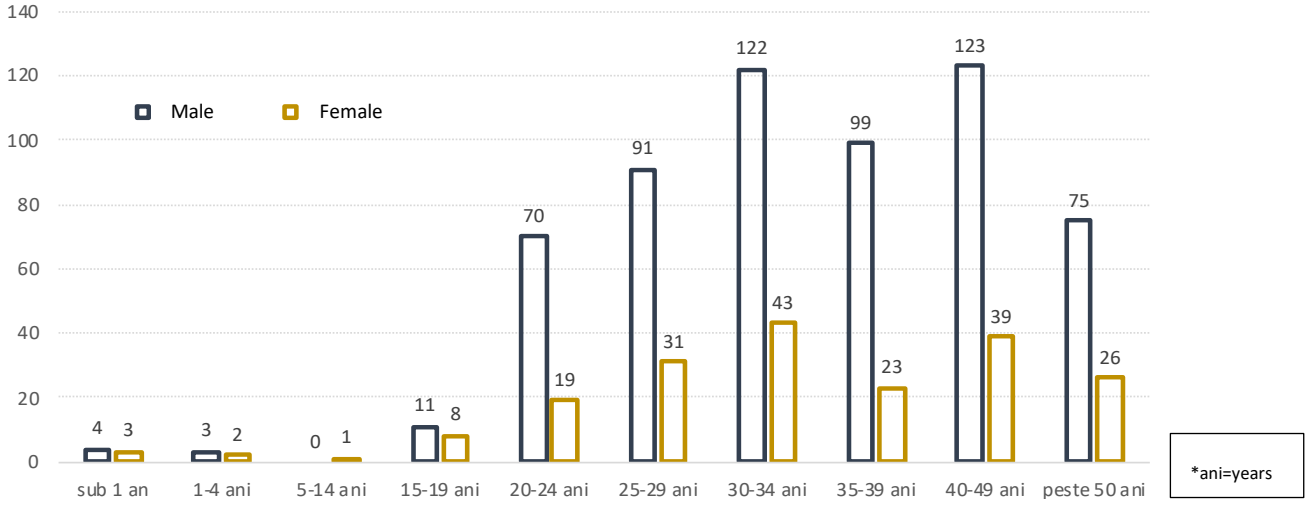
Annex 1. HIV statistics in Romania

Figure 4. The evolution of the number of newly diagnosed cases between 2009 and 2019



Source: The HIV/AIDS Monitoring and Evaluation Department of the National Institute of Infectious Diseases Prof. Dr. Matei Balș, 31 December 2019.

Figure 5. The distribution of new infections detected in 2019 by age group and gender



Source: The HIV/AIDS Monitoring and Evaluation Department of the National Institute of Infectious Diseases Prof. Dr. Matei Balș, 31 December 2019

Annex 2. Informed consent for participating in the study

To be completed by respondents participating in the qualitative research.

Please read this form carefully and ask any questions about your participation in this study before giving your consent.

You are invited to participate in a research on your personal experience with HIV/AIDS in Romania. The research is carried out by the NGO Romanian Angel Appeal (RAA) from January to March 2020. The aim of this is to better understand the challenges faced by people living with HIV/AIDS in Romania in order to inform public discussions and policies that adequately respond to these needs.

The research includes collecting the views of people living with HIV/AIDS in Romania. The opinions expressed by you will not be communicated to anyone in this form, they will only be used for research purposes. The questions are about your experience, there are no right or wrong answers. The study consists of questionnaires and interviews such as the one we invite you to participate in. In addition to these interviews, the research team also collects quantitative data through questionnaires.

Your personal data in this informed consent will be kept confidential, with only members of the project team and the funder having access to it. The processing of personal data is done in accordance with the relevant European legislation (GDPR). All data collected will be used for statistical research purposes ONLY. In case the data is published, no individual information will be disclosed.

Your participation in this study is voluntary and does not involve any risk to your health. You can withdraw from the research at any time without giving any explanation.

Your responses will be analyzed anonymously as part of the research report, planned to be finalized at the end of March 2020.

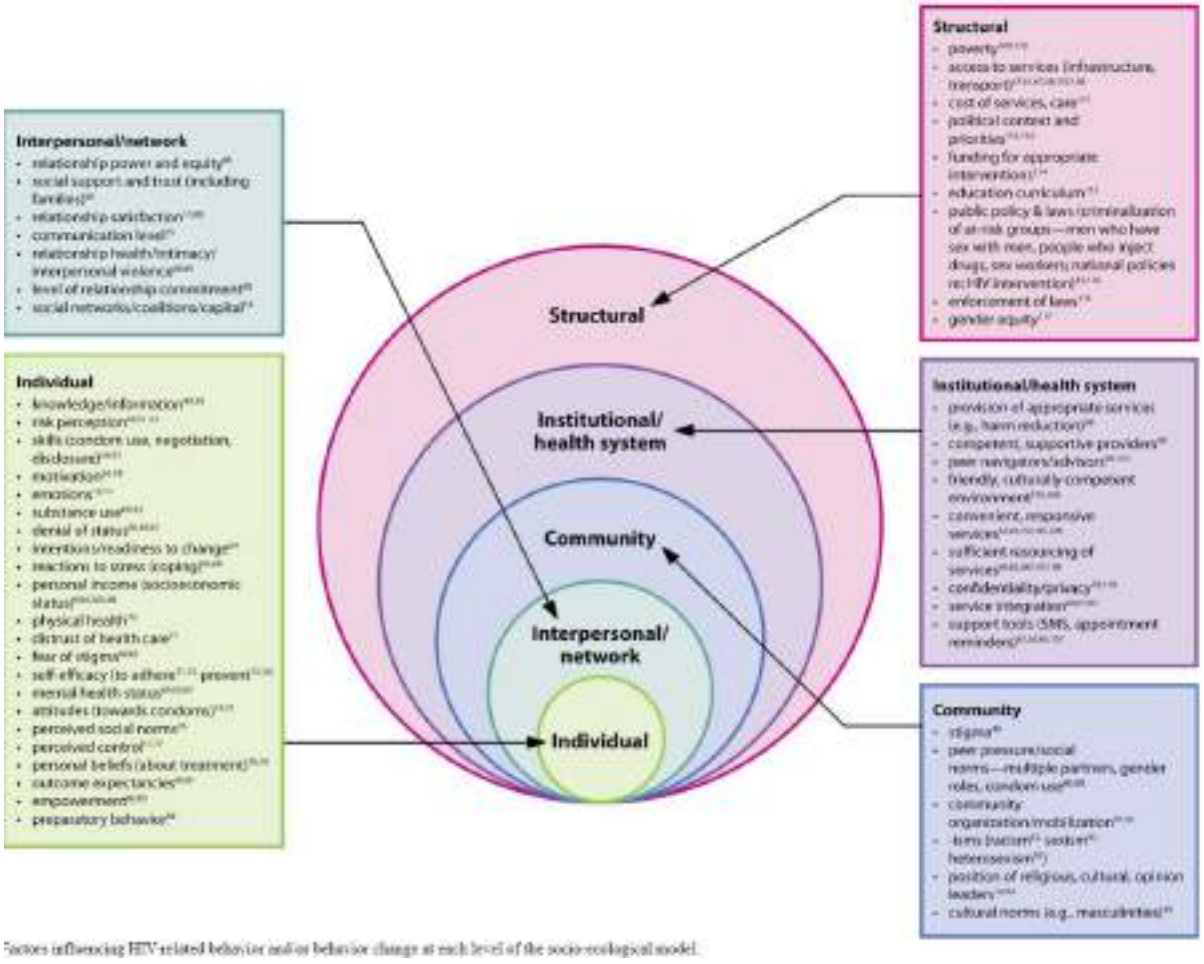
By signing this form, I confirm that:

- ✓ I can ask questions about research
- ✓ If requested, I have received the necessary clarifications
- ✓ I agree to participate in this study
- ✓ I have read and understood this consent form
- ✓ I understand that I can contact the national data protection authority - the National Supervisory Authority for Personal Data Processing – https://www.dataprotection.ro at any time, free of charge.

Full name _____

Signature: _____ Date: _____

Annex 3. Factors influencing the health behaviors of people living with HIV



Source: Kaufman, Cornish, Zimmerman and Johnson (2014).

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The research was conducted within the framework of the Romanian Angel Appeal Foundation's project "#SOS_Project: Partnership for sustainable public policies in the area of HIV/AIDS prevention", funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria.

The project was coordinated by Camelia Raita.