

A Qualitative Study of Systemic Barriers Encountered by HIV-Positive Immigrants in Spain

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Research article

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Abstract

Background: Immigrants are disproportionately impacted by HIV infection in Europe and in Spain. Immigrants are also identified as a vulnerable population during economic crises. Various socioeconomic barriers hinder HIV-positive immigrants from accessing healthcare services in the host country. As a result of the 2008 financial crisis, Spain has implemented multiple austerity measures, one of which was the enactments of Royal Decree Law (RDL) 16/2012 and Royal Decree (RD) 1192/2012 which abolished universal healthcare coverage. In this context, this study examined systemic barriers encountered by the participants while accessing health care after the enactments of 2012 RDL and RD. The study also researched distress felt by the participants and their experiences as HIV-positive immigrants living in Spain.

Methods: Participants were recruited through a nongovernmental organization (NGO) during routine visits at their center. A total of 12 participants were interviewed to reach data saturation. Participants were HIV-positive immigrants living in Spain for 1 or more years, allowing for substantial experience with navigating the healthcare system. Thematic analysis was performed to identify common themes in participants' experiences living as HIV-positive individuals in Spain and confronting systemic barriers to healthcare access.

Results: Four primary themes were identified. Participants identified experiencing emotional or physical (eg, side effects of medication) distress in adapting to life as HIV-positive individuals. Participants also expressed experiencing discrimination while living as HIV-positive immigrants in Spain. The primary systemic barrier to accessing health care encountered by participants was the inability to fulfill the requirement of having proof of registration in an Autonomous Community for the required time period, thus not being able to apply for a public health insurance card and utilize free care services. Participants identified a positive impact of third party (NGO, social worker, friend/family member) guidance on their experience of applying for a public health insurance card.

Conclusions: HIV-positive immigrants are underserved in Spain. They encounter systemic barriers while accessing healthcare services, and experience fear and/or discrimination. The study underscores the role of NGOs in helping HIV-positive immigrants navigate the healthcare system. More research is needed on comprehensive approaches to address healthcare needs of HIV-positive immigrants in Spain.

Background

More than half of European Union (EU) member states identify immigrant populations as disproportionately affected by HIV.¹⁻⁴ Since the mid-1990s, Spain has reported a disproportionate number of HIV cases among immigrants as compared with native-born Spaniards.¹⁻⁶ According to the first nationwide HIV data collection tool (Information System for New Diagnosis of HIV) implemented in Spain, of 3366 newly diagnosed cases (7.2 cases per 100,000) in 2014, 32% (1077.10 cases) were identified among immigrants.⁷

Socioeconomic insecurity, legal status of immigrants, and the experience of stigmatization in the host country affect immigrants' access to prevention programs, testing, and care services.^{2,8} This further creates inequalities in healthcare access among immigrants relative to the native-born population,⁹ and increases their vulnerability to HIV infection.^{4,5,8-13} Health policies¹⁴ and economic crises¹⁵⁻¹⁷ can also have a significant effect on overall population health. The impact of economic crises on vulnerable groups, such as immigrants, is also disproportionately severe.¹⁸

In recent years, Spain has executed multiple austerity measures to cope with the effect of the 2008 economic crisis. In 2012 the government enacted Royal Decree Law (RDL) 16/2012 and Royal Decree (RD) 1192/2012 that, together with other budget cuts, increased copayments for an already economically distressed population, denied the right to health care among the undocumented immigrant population,¹⁸⁻²⁰ and altered the previously exercised universal healthcare system in Spain.¹⁸⁻²¹ This created more barriers that immigrants encountered while accessing necessary healthcare services and added to discrimination or stigma commonly experienced due to HIV-positive status in a host country.²

HIV treatment disruption may cause health deterioration among immigrants and increase mortality and transmission of the virus.²² In this context, and in light of the paucity of data on HIV-positive immigrants in Spain, the aim of this qualitative research was to determine the systemic barriers experienced by HIV-positive immigrants while accessing necessary healthcare in Spain.

Methods

Participant recruitment

Twelve participants were recruited by a local nongovernmental organization (NGO) through phone or in-person contact during their routine visits to the office. The local NGO is dedicated to helping HIV-positive immigrants (eg, providing psychologic support as well as necessary nutritional food) and to guiding them through the process of accessing healthcare services in Valencia, Spain. To ensure participant anonymity, the name of the NGO is not listed. A social worker employed at the local NGO, otherwise not involved in the research, identified HIV-positive immigrants who routinely engaged with the organization and who met the criteria determined by the study. The social worker explained the purpose of the study to prospective participants. Refusal to participate in the study did not impact services provided to them by the NGO. Written informed consent (available in English and Spanish) was obtained. Participants were included in the study if they met the following criteria: 1) adults 18 years or older; 2) HIV-positive; 3) had been living in Spain for 1 or more years; 4) spoke Spanish or English; and 5) had experience accessing necessary healthcare as HIV-positive adults. All interviewees were given €10 to participate in the research. The study was approved by the City University of New York Institutional Review Board.

Interview procedure

Semistructured interviews were conducted at the partner NGO site in summer 2019 to facilitate in-depth conversations with study participants around sensitive topics. This method allows for a deeper understanding of participants' life experiences.²³ Interviews were conducted in Spanish by the lead author. Participants agreed to the recording of the interview to ensure the accuracy and completeness of the data captured.

Semistructured interviews were designed to explore participant experiences in the following 2 areas: 1) life as an HIV-positive person in terms of emotional or physical distress, and perceptions or experiences of discrimination; and 2) barriers to accessing healthcare services in Spain, and how/if they were able to overcome them. The semistructured interview guide (see Appendix 1) was designed in accordance with a conceptual framework by Lévesque et al²⁴ that concentrated on different levels of healthcare access, including participants' ability to identify healthcare needs, seek care, reach necessary services, obtain care, and receive adequate services. The Lévesque et al²⁴ framework has been previously validated among immigrants in various European countries.²⁵ Our interview guide also included questions exploring participant experiences when diagnosed as HIV-positive and the social effect it had on them. The final question in the guide addressed participants' knowledge of 2012 RDL and RD and if/how these impacted them.

Thematic analysis

Before performing analysis, all interviews were transcribed and deidentified. Transcription of the interviews was done by a professional service. Both transcription and subsequent analysis were performed in Spanish. Only quotes used in this paper were translated by the lead author from Spanish into English. Quotes were corrected for grammar and restructured for clarity without altering the meaning of the original speech.

Thematic analysis identified commonalities among the participants. Thematic analysis was chosen for this study as it allowed for the richness of capturing stories,²⁶ as opposed to using a predetermined framework to analyze the data. The interviews were analyzed following Braun and Clarke's²⁶ guidelines for thematic analysis. Dedoose (version 8.3.16) was used to aid the analysis.

Results

Characteristics of the participants

Data were considered sufficiently saturated after in-depth interviews with the 12 study participants. Table 1 shows the characteristics of the participants. Participants were from 6 different countries (Argentina, Chile, Cuba, Honduras, Peru, and Venezuela) and all spoke Spanish as a native language. Five of the 12 participants were employed and 4 were married or in a relationship. Sex distribution was approximately equal among women and men; 60% of the participants were between the ages of 31 and 50 years. Five participants were heterosexual, 5 were homosexual, and 2 identified no sexual preference. Half of the participants had lived with HIV from 6 to 25 years; 50% of participants had resided in Spain from 1 to 5 years and the rest for 6 or more years. Regarding immigration status, 60% of the participants arrived in Spain without documentation and 60% of participants were documented at the time of the interview. Half of the participants arrived for the first time in Spain alone. Reasons for immigration varied among the participants; most reasons related to financial or political hardship.

Table 1
Characteristics of the Participants

| | |
|---|----|
| Sex | |
| Women | 6 |
| Men | 5 |
| Transgender women | 1 |
| Age, y | |
| 18–30 | 2 |
| 31–50 | 7 |
| 51–65 | 3 |
| Sexual orientation | |
| Heterosexual | 5 |
| Homosexual | 5 |
| Unknown/other | 2 |
| Region of origin | |
| Argentina | 2 |
| Chile | 1 |
| Cuba | 3 |
| Honduras | 1 |
| Peru | 1 |
| Venezuela | 4 |
| Employment status | |
| Employed | 5 |
| Unemployed | 2 |
| Part-time employment | 1 |
| Illegal manual work | 3 |
| Retired | 1 |
| Family status | |
| Single | 8 |
| Married | 2 |
| In a relationship | 2 |
| Number of years diagnosed with HIV | |
| < 5 | 4 |
| 6–15 | 1 |
| 16–25 | 5 |
| 26> | 2 |
| Probable transmission mode | |
| Heterosexual contact | 5 |
| Homosexual contact | 5 |
| Unknown | 2 |
| Initially tested in Spain | |
| Yes | 1 |
| No | 11 |

Table 2 shows their brief immigration journeys. Table 3 summarizes participant experiences with being HIV-positive in Spain and in their countries of origin.

Table 2
Immigration Details of the Participants

| | |
|---|---|
| Time living in Spain, y | |
| 1–5 | 6 |
| 6–11 | 1 |
| 12–16 | 2 |
| 17> | 2 |
| Unclear | 1 |
| Documentation status when arrived | |
| Documented | 5 |
| Undocumented | 5 |
| Asylum seeker | 2 |
| Documentation status now | |
| Documented | 7 |
| Undocumented | 3 |
| Asylum seeker | 2 |
| Immigrated to Spain alone | |
| Yes | 6 |
| No | 6 |
| Living with partner/family member | |
| Yes | 6 |
| No | 5 |
| Unknown | 1 |
| Reason(s) of immigration | |
| Financial situation of country of origin | 3 |
| Political situation of country of origin | 3 |
| Health reasons | 1 |
| Political situation and health reasons | 1 |
| Other (Spanish partner, threat to life in the country of origin, financially supporting child already living in Spain, seeking treatment for a family member) | 4 |

Table 3
Participants' Experiences Being HIV-Positive

| | |
|---|---|
| Family/friend support on the matter of HIV | |
| Full support (family and friends) | 2 |
| Family support | 1 |
| Friend support | 2 |
| Some support (some family and/or some friends) | 6 |
| No support | 1 |
| Experience/perception of country of origin context for HIV | |
| Lack of medication | 5 |
| Discrimination (including fear of discrimination) | 2 |
| Stigma and prejudice (including lack of information) | 4 |
| No experience in country of origin | 1 |
| Received initial guidance on how to access necessary healthcare services in Spain | |
| NGO guidance (including associations) | 6 |
| Hospital staff (social worker) | 1 |
| Friend guidance (friend, family member) | 5 |
| Experience of applying for insurance card in Spain | |
| Positive | 9 |
| Negative | 3 |
| Perceived reasons for negative experience while trying to access healthcare services or after receiving care | |
| Hospital staff (not entitled to health insurance card) | 1 |
| Not entitled by the law (3-month registration requirement not met) | 2 |
| Not explained the system in advance (received a bill) | 1 |
| N/A (participants who did not identify negative experience) | 8 |
| Perceived experience while trying to access other health services/follow-ups | |
| Positive | 9 |
| Negative | 1 |
| Unknown or not applicable | 2 |
| Emotional experience of living with HIV | |
| Distress | 4 |
| Distress in the initial stages | 5 |
| No negative thoughts expressed | 3 |
| Experience of discrimination in country of origin | |
| Fear of discrimination | 5 |
| Experienced discrimination | 2 |
| No experience of discrimination | 1 |
| Other (unknown or not applicable) | 4 |
| Experience of discrimination in Spain | |
| Fear of discrimination | 2 |
| Experienced discrimination | 2 |
| No experience of discrimination | 3 |
| Other (felt differential treatment, unknown, unclear) | 5 |
| Knowledge/experience of 2012 RDL and RD | |

| Family/friend support on the matter of HIV | |
|---|---|
| Aware and did not change anything | 1 |
| Somewhat aware and did not change anything | 3 |
| Not aware and was not in the country | 4 |
| Not aware and was in the country | 1 |
| Not aware and unclear if he/she was in the country | 3 |
| NGO, nongovernmental organization; RD, Royal Decree; RDL, Royal Decree Law. | |

| Table 4. Themes Identified through the Interviews | |
|---|---|
| Theme | Brief Description |
| Experienced distress after being diagnosed HIV-positive | Participants experienced emotional or physical distress and/or struggled to adapt to living as an HIV-positive person during initial period of diagnosis, throughout life, or described no negative time in their lives as it pertains to the adjustment to being HIV-positive. |
| Perceived and experienced discrimination due to being HIV-positive while in Spain | Participants had perceived fear of discrimination, experienced discrimination, experienced differential treatment, ignorance about HIV, as well as described not having any discriminative incidents as an HIV-positive person. |
| Barriers encountered when initially trying to access free healthcare services in Spain | Participants experienced systematic barriers (not being eligible to receive public health insurance card) and administrative barriers (front office staff at the hospitals) while trying to access free healthcare services in Spain. |
| Possible reasons of positive experience when initially trying to access free healthcare services in Spain | Participants identified sources who gave them initial guidance on the process of receiving free healthcare services and were perceived by the interviewer as a possible reason of overall positive experience. Specifically, guidance from an NGO, from a friend, hospital staff, or personal effort. |
| NGO, nongovernmental organization. | |

Main themes identified

Table 4 presents 4 themes identified during the interviews. All 4 themes address life experiences of the participants and the systemic barriers and/or enablers they encountered while initially trying to access healthcare services in Spain.

A. Theme 1: Experienced distress after being diagnosed HIV-positive

The majority of participants expressed difficulty with accepting becoming HIV-positive, with managing the health effects of having HIV or of its treatment, and with sharing the diagnosis with loved ones. For example, Patient 2 shared the following anecdote:

Patient 2: *"At the start I was very depressed. In my case I had a shock and it took me 15 years to talk about it, and I talked about it in AVACOS-H. It was incredible horror, panic, the world came down on me, I had adolescent children, and they were in the waiting room at the hospital. One of them heard the diagnosis and told the other. They found out like this, because if it was for me, I would just have carried this alone."*

(AVACOS-H is a Valencian Association dedicated to HIV, AIDS, and hepatitis.)

Similarly, Patient 4 described experiencing distress due to the process of accepting the diagnosis and sharing it with loved ones.

Patient 4: *"My experience when I came here was very bad, emotionally. This man, at the NGO, who I think is a psychologist, talked to me a lot and helped me understand many things. He told me that I am not the first or the last who is going through this. I had fear for my family as well because they were asking me how I was and what happened. Only my 3 daughters know about it. I did not want to know anything about anyone, because I had fear of restarting my life. I had a Spanish boyfriend and he did not know either."*

In the same vein, Patient 5 described experiencing distress due to the process of assuming the diagnosis and sharing it with the family, and also dealing with the treatment side effects.

Patient 5: *"(...) They told me that I was HIV-positive and you can imagine what I was thinking, oh my God, my little children, my husband. They told me do not worry, that you can last for 10 years. Imagine it was 2003, I had 7- or 8-year-old kids and another who was 12 or 13 years old. So little, and imagine they tell you this, that you can last 10 years, my head went crazy. In the end I started the treatment, but it gave me an incredible allergy. I could not wear clothes because everything was itching, another [medication] made me vomit, and I could not walk, but I was looking in the mirror and every time I was seeing myself marked by another treatment. Because all treatments were hurting me I stopped taking them and I spent one and a half years without any treatment before I came to Spain. The second treatment that they gave me here was effective (...) My friends did not know because there [referring to her country of origin] you could not say this. Sincerely I did not have any support."*

Similarly, other participants, such as Patient 7, expressed difficulties due to lack of treatment in their countries of origin, and had the following reaction after being diagnosed:

I will die. I thought that I will die.

Another participant (Patient 10) expressed that it was necessary to be positive; however, it was hard to initially adjust to the knowledge of being HIV-positive.

Patient10: *"If you are positive, it will give you a lot of fear; you are scared to enter this world, because it is not easy. You go to bed thinking that you have the disease and you wake up knowing you have the disease and it is hard. In the beginning it is hard to overcome this thinking, it is hard to overcome, but when you accept it then you know that you will live with this until the end of your days."*

A few participants did not express having strong emotional distress due to being diagnosed with HIV. They took care of themselves (received treatment, lived a healthy lifestyle); however, they nonetheless avoided sharing information with others.

Patient 1: *"When I found out about it, I knew I had to live a bit differently, and did not get upset. So, I was taking care of myself. Especially when I was not taking any medication, so I ate well and slept well. Because I did not have a medication, I was limiting my life a bit. I do not feel like I have HIV. I go on as if nothing happened to me."*

Few participants expressed no or limited emotional distress while dealing with their diagnoses or life as HIV-positive persons, contrary to the majority of immigrants who were interviewed. For example, Patient 3 shared the following:

Patient 3: *"(...) I got it and that is it, it is something that you do not choose (...) you have to accept it. I think I accepted it quite well. However, it was still a process of adaptation (...) I know that I have it, but it is controlled (...) sometimes I do not believe that I have it. I know that it is there and I take care of myself, I take my medication (...)"*

Another participant (Patient 6) explained that, although it was hard to adapt to the idea of being HIV-positive, the support of her partner made it manageable for her.

Patient 6: *"For me it was hard, it is a hard situation. Knowing that you are limited in many things (...) but I was lucky to have a partner, we were together, we were in the same situation (...) I cannot imagine people who are alone, people who do not have support of a partner or family members or of a friend or similar, because friends discriminate too."*

B. Theme 2: Perceived or experienced discrimination due to being HIV-positive in Spain

The majority of participants experienced discrimination or expressed fear of possible discrimination due to their HIV status. For example, Patient 12 said the following:

Patient 12: *"We went to a pool in a village and the owner told his subordinates not to let us in the pool because we will contaminate everyone with AIDS. In the hospital as well. I was in the observation room and I asked someone for water. He was slow to bring it and I heard them talking. I heard one worker telling another that he should be careful with me because I have HIV. I got angry and I told them, "I will not contaminate your fellow worker if he brings me a glass of water."*

Patient 11 also noted how she was treated differently due to prejudice or lack of knowledge about HIV and how it could be transmitted.

Patient 11: *"I lived with my niece who was living with her aunt. This woman knew of my health condition but her children did not. Once I was cooking a stew and I took a spoon to try it and she [referring to the aunt] thought I was planning to put it directly to my mouth. She told me "put it in your hand." I told her, "I was planning to do that." I saw where this was going. She was asking, "How are you?" "You have to be careful with these things." Of course, I was very careful, including after I showered. I leave the bathroom as if no one has entered it."*

Some participants described having fear of discrimination in different situations in their lives in Spain.

Patient 10: *"It is a country with people of different ages, and you cannot compare a person who is 80 or 70 years old with one who is 20 years old. Older people bring a lot of stigma and taboos to many situations. It does not matter how much you say that Spain is free and is diverse and there are a lot of liberties, the society here is still trying to accept things."*

Patient 10 also talked about perceived fear of being denied employment or being fired because of his HIV status.

Patient 10: *"One also has fear in an environment of employment when you think "They will do a test for HIV and it will come out positive, and they will fire me, they will not want me, they will reject me."*

Similarly, Patient 2 described her actual experience when trying to get a job.

Patient 2: *"Recently, in some jobs they no longer discriminate because of age and HIV status, because in some other jobs they continue to reject you for other reasons, but in reality, because they do analysis and HIV status comes out positive. Because they want to be sure that people will not miss work, contracts are short, they want to get rid of a lot of problems. They think that people who have HIV will be constantly in the hospital."*

On the other hand, Patient 8 described a violation of her right to doctor-patient privacy because she had HIV.

Patient 8: *"My partner did not know it [referring to her HIV status], and when I told my doctor, I felt liberated. This doctor made me feel safe, but when I left the room and my partner entered, he told him "How is it going with your partner, so many years as a HIV patient?" When he came out of the room, he gave me a look. I wanted to report him [referring to the doctor] because it should not be like this, because supposedly I am signing a document that says that whatever I tell my doctor is confidential."*

Few participants expressed limited or no experience of discrimination or perceived discrimination due to being HIV-positive, however their responses were nonetheless telling of the broader social conditions around HIV. For example, Patient 1 shared the following:

Patient 1: *"Because I never shared and I never talked about it, I never had this experience."*

C. Theme 3: Barriers encountered when initially trying to access free healthcare services in Spain

The majority of participants who had negative or somewhat negative experiences while trying to access free healthcare services mentioned encountering systemic barriers; specifically, not being able to receive a public health insurance card. Patient 3 discussed problems with meeting the requirement of being registered in an Autonomous Community (AC) for the minimum months required in order to apply for a public health insurance card.

Patient 3: *"Applying for a public health insurance card was a problem at the start, because I arrived in Spain and here it is fundamentally important to be registered in an AC. I spent 4 months without meeting someone who would register me in the AC. I was paying rent but no one ever registered me there. I got registered in my fourth month in the AC."*

Similarly, Patient 11 described problems with meeting the requirement of being registered in an AC in order to apply for a public health insurance card.

Patient 11: *"Everything had to be done one after another. Analysis, applying for a public health insurance card especially, because I was not previously registered 3 months in the AC as they required. I did not have that yet. They asked me for the proof of registration in the AC and I just gave an address of the place I arrived to."*

Another participant (Patient 6) had difficulty getting an appointment with the social worker at the hospital to apply for the public health insurance card. According to the participant, he thought the social worker could grant a public health insurance card, as advised by a friend.

Patient 6: *"The admission and information desks at the hospitals need a reason why you want an appointment with the social worker. They were telling us different reasons why they could not give us an appointment with the social worker. They told us that in order to get such an appointment we already needed to have a public health insurance card. We explained that we did not have the card and that is why we wanted an appointment, but they told us that the social worker was not for that. We went there because our friend received the card this way, but in another institution or health center."*

When the interviewee was asked if the admission or information staff at the hospital explained where they should have gone to apply for the card, Patient 6 answered *"No, they never told us."*

Few participants expressed limited to no barriers while trying to access healthcare services in Spain. For example, Patient 2 shared the following:

Patient 2: *"(...) I was talking to the people with the truth, I was telling them, "listen, we are trying to have a normal life in Spain, have all of our documents in order, we do not want anyone to give us gifts", but it could have been because I am HIV-positive they were immediately giving me an public health insurance card with validity of 3 months, 6 months, depending on the regional government (...)"*

Patient 6 also expressed experiencing no barrier in receiving a public insurance card necessary to access free healthcare services in Spain.

Patient 6: *"Here in Spain, I was given one paper that allows me to live in Spain so I did not have any problems, look here it is (...) for all the hospitals."*

D. Theme 4: Possible reasons of positive experience when initially trying to access free healthcare services in Spain

This theme expresses the notion of a "guiding source" who possibly influenced participants' positive experiences when initially trying to navigate the public health system in Spain. The majority of the participants mentioned guidance from a local NGO who showed them pathways to receiving free healthcare services and a public health insurance card. They found an NGO through personal effort or a friend. Patient 11 described her experience of trying to receive treatment for HIV in Spain through the help of a local NGO, as follows:

Patient 11: *"I came here with enough medication for one month. When it was gone, I thought, "What do I do now?" I searched on the Internet and I said, "There should be some organization here dedicated to HIV-positive people that can help me in this situation." I found AVACOS-H. I called them and they answered and asked me, "Can you come in now?" Of course, I went because I had been without medication for two weeks. When I explained my situation and how I was, Diana helped me a lot. She immediately talked with a doctor for me."*

Similarly, Patient 10 described how everything was organized for him by a local NGO as follows:

Patient 10: *"The Red Cross guided me to receive a public health insurance card: right away they helped me talk with a doctor who gave a referral, after which I went to ambulatory care and talked with a social worker to whom I explained my health needs and that I needed treatment. Right away I was given a health*

insurance card and a doctor gave me the treatment I needed.”

Several participants shared how friends guided them through the process and helped navigate the system. For example, Patient 1 expresses how a friend, who immigrated to Spain before him, explained to him where to go and what to do.

Patient 1: *“I came here with help from my friend from Cuba. He came here two months before I did. Thus, he already navigated all these formalities and he explained to me what I had to do. I went to the medical center. But I was not registered in the AC. I explained that I was HIV-positive and that I had to take a medication. I talked with a social worker and she processed everything for me.”*

In the same vein, P12 noted the following:

Patient 12: *“A man that I was married to was coming to Valencia (...) When he arrived, he told me “do not pay anything.” I received a bill at the hotel where I was staying. He told me, “Do not pay anything and this will be resolved.” I went back with him [to the hospital] and that is when I started doing all the paperwork and public health insurance card...”*

Similarly, Patient 9 talked about how a friend helped her complete the requirements to receive a public health insurance card and guidance received from a local NGO to pursue other possible help.

Patient 9: *“Yes, the woman in the apartment where I was living helped me get proof of registration at this address. AVACOS-H also helped to see if I could receive financial assistance.”*

All participants shared having some level of guidance from a third party (such as an NGO, hospital staff, or a friend) that helped them navigate the Spanish healthcare system.

Possible influence of other variables on the positive experience

The study also looked at the possible connection of the documentation status of the participants and/or of the type of guidance received, on positive or negative experience when applying for a public health insurance card. All participants who arrived in Spain with legal documents (5 of 12) or as an asylum seeker (2 of 12) had a positive experience when applying for a public health insurance card. Four out of these 7 participants received guidance from an NGO through the process, 2 were assisted by friends, and 1 was aided by a hospital staff member.

Of the 5 participants who arrived in Spain undocumented, 3 had negative or somewhat negative experiences while applying for their public health insurance cards. Two undocumented participants had a positive experience. Of these 2 latter participants, 1 was guided through the process by an NGO and another was guided by a friend who initially was also assisted by an NGO. Of the 3 participants who had negative or somewhat negative experiences, 2 had minimal guidance from a friend and resolved the obstacles by themselves. The third undocumented immigrant had to access emergency care due to an accident for which she was billed. After receiving the bill, she was advised by a family member not to pay the bill. This participant already had legal immigrant status in Spain when she needed healthcare services for the first time.

Discussion

The number of immigrants in Spain has increased greatly over the past decade. In 1998, immigrants were only 1.6% of the total population; by 2019, the percentage had increased to 10.7%.²⁷ It is commonly observed that immigrants arrive healthy in the country (healthy immigrant effect)^{28,29}; however, with the passage of time, their health worsens due to various socioeconomic factors and to the risk of being excluded from free public health services.^{30,31} Few studies have examined the process of access to healthcare services among HIV-positive immigrants in Spain.³² To our knowledge, this is one of the first studies to examine the experiences of this vulnerable population in Spain, especially after the passage of 2012 RDL and RD. This study adds new knowledge to the public health literature, highlighting the personal and systemic struggles faced by HIV-positive immigrants in Spain, in both health care and other arenas.

We found that all participants who encountered barriers while applying for a public health insurance card mentioned not having proof of registration in an AC (with or without the required minimum time period of residence) as an obstacle (Theme 3). Participants who had a somewhat positive experience of applying for a public health insurance card were guided by a social worker, a friend, or family member or an NGO/association (Theme 4). Participants who had somewhat negative experiences while applying for a public health insurance card reported less guidance from another person or organization. Sixty percent (7 of 12) of the participants did not appear to have knowledge of the 2012 health reform in Spain and thus did not express its effect on their lives. Only 1 participant was fully aware of the health reform.

Results are consistent with other studies that identified difficulties individuals had meeting legal requirements to use free healthcare services, including acquiring a public health insurance card, which were barriers to access to care in Spain. Being an undocumented immigrant has also been identified as a risk factor for facing more barriers while accessing healthcare services.^{33,34} The 2012 RDL and RD abolished previously practiced universal healthcare access in Spain,³⁵ and the requirement of being registered in an AC was a barrier stemming from the new law. Therefore, regardless of whether participants were aware of the 2012 RDL and RD, the commonly cited systemic barrier to accessing a public health insurance card was the direct effect of 2012 RDL and RD.

This study highlights the importance of the existence of NGOs and social networks in facilitating HIV-positive immigrants' access to free healthcare services. Even when individuals are not directly engaged with an NGO, it can still be the source of informational or instrumental support for family and friends who try to help. NGOs appear to be an important safety net system in Spain and appear to buffer against restrictions that Spanish laws imposed on healthcare access among undocumented immigrants. We have found previously that regional implementation of the national laws varied greatly, with some ACs eventually granting access to undocumented immigrants who were HIV-positive, but navigating these provisions was often difficult for individuals (Unpublished data).

Previous studies have also shown that third-party guidance is a positive facilitator for entry into the healthcare system in Spain.^{34,36} Various NGOs and medical communities in Spain have been actively involved in advocating for the rights of immigrants to health care, especially after the implementation of 2012 RDL and RD.³⁵ Some of these organizations have also been providing administrative support or healthcare assistance to immigrants who were initially denied care.³⁶ Furthermore, having a robust civil society may be crucial for mobilizing advocacy and policy action in the face of political ideology that is not public health-friendly in many ACs; political ideology can often influence how each AC implements national laws on healthcare access.³⁷

Experiences (or fear) of discrimination, stigma, and intolerance have been previously reported by HIV-positive immigrants in Spain and other European countries,^{25,34} as has the burden and struggle of their health status.²⁵ This highlights the importance of disseminating information on available support services (hospitals, health centers, pharmacies, other community organizations) and providing proper education and adequate support to all HIV-positive immigrants, especially because many immigrants come from countries with stigma and intolerance regarding HIV. The need for comprehensive systems intervention to address the multifaceted challenges faced by HIV-positive immigrants in Spain is further reinforced by findings from this study.

We recognize some limitations of our study. First, our sampling from a single site may limit the generalizability of the results. However, findings are consistent with the results and recommendations of previous studies on the topic of interest.^{25,33-36} Second, this study has a small sample size, which may limit variations in the explored topic.³⁸ However, data reached saturation with 12 participants in our study, suggesting that the sample was sufficient for the issues investigated and in the particular study setting. A smaller number of participants also allowed in-depth case-oriented analysis of each interview which is a strength in qualitative research.³⁸ Another limitation is the possible impact of the face-to-face interview process on underreporting of participants' experiences as HIV-positive persons living in Spain. However, the interviewer came from a social work background and created a safe and motivating environment for the interviewees in which to freely tell their stories. Finally, although questions for the interviews were designed specifically for this study, it is possible that a different set of questions could have given different results. However, the interviews were semistructured, which allowed interviewees to deviate from the questions. This allowed exploration of participants' lives as HIV-positive immigrants in Spain that was not initially included in the semistructured interview guide.

Conclusions

This study is a contribution to the limited literature describing the personal journeys of HIV-positive immigrants and their experiences accessing healthcare services in Spain, especially after the passage of 2012 RDL and RD. Immigrants represent a growing population in Spain, and all of Europe, and greater public health attention to the needs of such vulnerable populations is urgently needed. The results of this study demonstrate the important role of NGOs in helping HIV-positive immigrants navigate the system. Future follow-up research is needed to design and implement effective models of improving the care and health of HIV-positive immigrants in Spain and throughout Europe.

Abbreviations

HIV
Human Immunodeficiency Virus

Declarations

Ethics approval and consent to participate

The study was approved by the City University of New York Institutional Review Board. Written informed consent (available in English and Spanish) was obtained from all the participants.

Consent for publication

Not applicable.

Availability of data and materials

The datasets generated and/or analyzed during the current study are not publicly available due to the small sample size and personal and confidential nature of qualitative information.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

MG conducted the data collection, analyzed and interpreted the data, and drafted the article. MG was responsible for integration of the feedbacks from other authors and finalization of the article for publishing. TH supervised the study. TH, KF, and SC provided profound feedback, and rigorous in-text editing of the article. TH, KF, and SC conducted several critical revisions of the article and provided approval of the final version.

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